IOWA MENTAL HEALTH AND DISABILITY SERVICES WORKFORCE REVIEW

Prepared for the Division of Mental Health and Disability Services of the Iowa Department of Human Services

By
The Annapolis Coalition on the Behavioral Health Workforce
In partnership with
The Mental Health Program
Of the
Western Interstate Commission for Higher Education

March, 2008

IOWA BEHAVIORAL HEALTH WORKFORCE REVIEW

About this report: As part of an on-going consultation with the State of Iowa, the Annapolis Coalition[1] was commissioned to provide a comprehensive review of workforce issues impacting the mental health and disabilities systems. The Coalition partnered with the Mental Health Program of the Western Interstate Commission for Higher Education, whose work on this report was funded by the National Association of State Mental Health Program Directors.

In addition to reviewing reports and data generated in Iowa, the team preparing this report researched national data bases and other sources to provide context. Interviews were held with a range of consumers, providers and state officials in completing this review. We acknowledge with gratitude the special efforts of Dr. Allen Parks, Dr. Bob Bacon, and Dr. Michael Flaum in providing background for this report, but any errors in the report are the full responsibility of the authors.

"Workforce" is a broad and potentially daunting topic. There are, to use a common vernacular phrase "a lot of moving parts." This review is therefore organized into discrete elements, many of which can be studied in relative isolation from other sections of the report. Preceding the topic specific sections is an overview vision for a changed workforce and some synopses of relevant Iowa workforce data. The report concludes with some over-arching recommendations to serve as guideposts for further elaboration of a comprehensive workforce reform agenda.

We thank all who contributed to our work, and who made us welcome during our visits to Iowa.

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[1] The Annapolis Coalition on the Behavioral Health Workforce is a national, not-for-profit organization created to increase awareness of critical workforce issues and to provide expert technical assistance to states and other organizations seeking to increase the quantity and competency of individuals who provide services and supports. Additional information available at www.annapoliscoalition.org.

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OVERVIEW, VISION AND PRIORITIES

Virtually every state in the nation is experiencing the leading edge of a growing workforce crisis in its behavioral health workforce; Iowa is no exception. And we note at the outset of this report that "workforce" has to be understood as an inclusive term, encompassing not only the traditional paid workforce that provides services and supports to individuals with mental, developmental or substance use conditions, but also those individuals who experience these conditions, as well as their families. The Annapolis Coalition, in partnership with the Mental Health Program of the Western Interstate Commission for Higher Education, has prepared this overview report at the request of Allen Parks, EdD, MPH, Director/Administrator, Division of Mental Health and Disability Services, Iowa Department of Human Services.

Since his appointment to head the Division of Mental Health and Disability Services, and with the active support of Commissioner Kevin Concannon, Dr. Parks has recognized the urgency of addressing Iowa's workforce shortages. According to the just released *The Future of Iowa's Health and Long Term Care Workforce*[2] Iowa ranked "47th among states in psychiatrists per 100,000 population and 46th for psychologists per 100,000 population in 2000. In addition, the professions serving the mental health needs of Iowans exhibited the highest combined percentage of licensed professionals age 55 and older (approaching retirement). It concluded that Iowa is likely to lose a considerable number of experienced mental health professionals in the next 10 years due to retirement." (p.20). The crisis reflects itself not just in the numbers of professionals available to provide services, as reflected in these data, but also the quality of their pre-service education and continuing education.

Further complicating the workforce picture are historic issues of recruitment and retention, a national set of problems made more vexing by the realities of Iowa's rural and frontier status.

All of these challenges come to bear at a time in which there is exponential growth in the science of effectively treating people with behavioral health conditions as well as those with dual- or multiply-co-occurring conditions. In order for Iowa to deliver evidence-based services, there must be a workforce sufficient in both numbers and training to deliver them.

Commissioner Concannon and Director Parks have a vision of a transformed service delivery system that demands new approaches to workforce development, building upon the strengths of the existing system.

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[2] The Future of Iowa's Health and Long Term Care Workforce, December 2007 Iowa Department of Public Health

Dr. Parks has expressed this vision

> *To build a skilled mental health and disability services workforce, including consumers and their families, that will work in local communities, community mental health centers, key state agencies, and service organizations to implement efficient, appropriately applied, and evidence-based services that significantly expand the role of individuals in recovery and their families when appropriate, to participate in, ultimately direct, or accept responsibility for their own care; provide care and supports to others; and educate the workforce.*

The highest priorities for the system focus on key service or population issues, among them the most pressing are:

- Community based services for children, adolescents and their families
- Community based services designed to prevent or quickly intervene in instances of behavioral health crisis
- Community based services for individuals with co-occurring condition, especially people with both mental and substance use conditions and those with both developmental and behavioral conditions.
- Strengthening the effectiveness of front line supervision in all parts of the system to support front line service providers.

THE CURRENT IOWA BEHAVIORAL HEALTH WORFORCE

Overview

The April 2002 report of the President's *New Freedom Commission on Mental Health* described in detail the significant problems facing mental health systems throughout the country. These include critical gaps in accessibility to services, shortages in the availability of providers and programs, limited acceptability of care due to stigma, and establishing mental health policy without consideration of its impact, to name just a few. These workforce disparities are especially evident in underserved populations and communities (e.g., rural, economically disadvantaged, ethnic minorities).

The President's *Commission* report acknowledged that incremental reform of the mental health system is no longer a viable option; a fundamental transformation is needed. As indicated in the "Vision Statement" of the report:

> "We envision a future when everyone with a mental illness will recover, a future when mental illnesses can be prevented or cured, a future when mental illnesses are detected early, and a future when everyone with a mental illness at any stage of life has access to effective treatment and supports — essentials for living, working, learning, and participating fully in the community" (p. 1).

A strong and stable behavioral health workforce is necessary in order to attain and maintain this vision.

Behavioral Health Workforce Shortages: A National Issue

Multiple reports dating from the Eisenhower era Presidential Commission on Mental Health through today indicate that the behavioral health workforce shortage problem is persistent with little improvement.[3] This is particularly true in rural and frontier areas (see section on Rural Workforce Strategies, page 58).

Health Professional Shortage Areas (HPSAs) are federal designations based on criteria created under Section 332 of the Public Health Service Act[4]. HPSA determination criteria include 1) urban versus rural geographic areas, 2) population groups, and 3) facilities with potential shortages of health professionals. Designations are intended to identify

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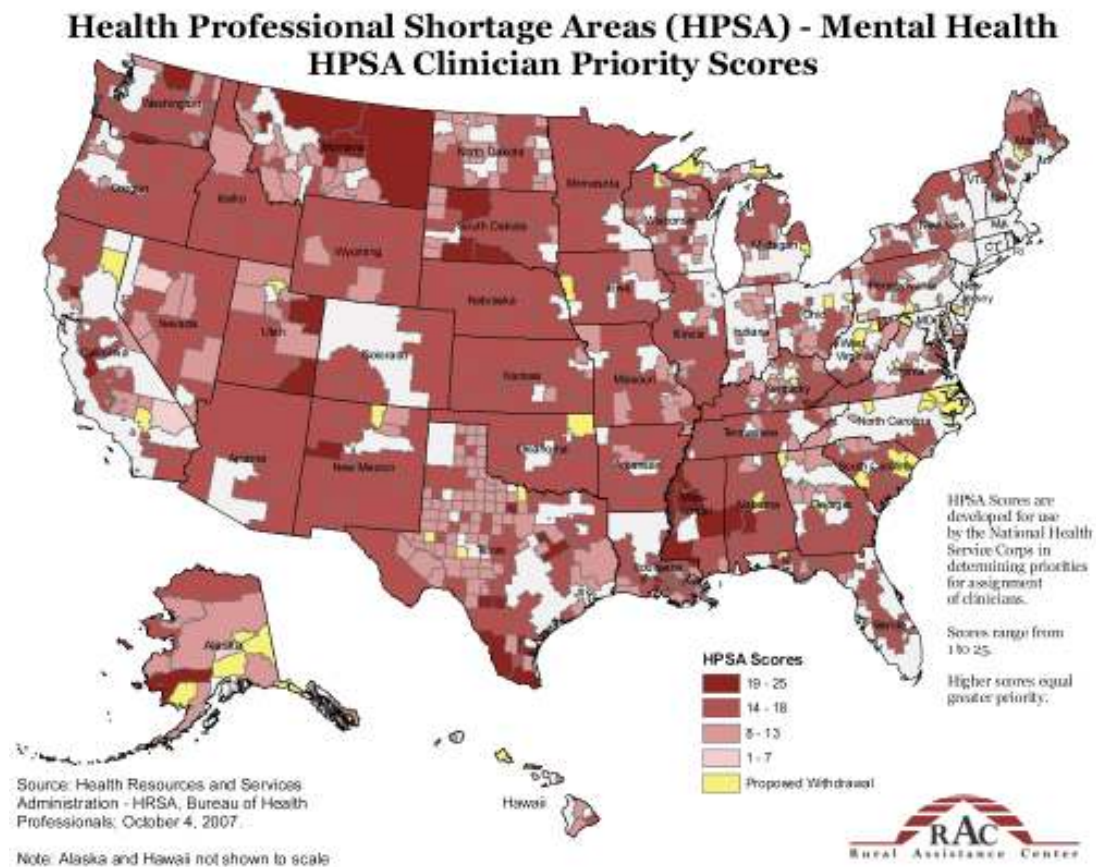[3] Bird et al., 1999; Flax et al., 1979; Larson et al., 1994; Murray & Keller, 1991

[4] U.S. Department of Health and Human Services Health Resources and Services Administration – Bureau of Health Professions. Health Professional Shortage Area Guidelines for Mental Health Care Designation. Available at http://bhpr.hrsa.gov/shortage/hpsaguidement.htm

communities with diminishing health care services and to provide them with opportunities for improved access to and availability of care. Mental health HPSAs indicate desirable ratios of population to "core" mental health professionals, namely psychiatrists, clinical psychologists, clinical social workers, psychiatric nurse specialists, and marriage and family therapists. Eligible communities can apply for state and federal assistance to recruit and retain health professionals, access additional reimbursement dollars, and request assignment of National Health Service Corps personnel to their area.

The map below shows the mental health professional shortages nationally.

Map 1: Designated Mental Health Professional Shortage Areas:
Nationally[5]

Health Professional Shortage Areas (HPSA) - Mental Health
HPSA Clinician Priority Scores

HPSA Scores are developed for use by the National Health Service Corps in determining priorities for assignment of clinicians.

Scores range from 1 to 25.

Higher scores equal greater priority.

HPSA Scores
19 - 25
14 - 18
8 - 13
1 - 7
Proposed Withdrawal

Source: Health Resources and Services Administration - HRSA, Bureau of Health Professionals; October 4, 2007.

Note: Alaska and Hawaii not shown to scale

Federal, Regional and State Activities

Efforts to address behavioral health workforce shortages have been underway for several years. At present, there is a national endeavor to increase attention to the behavioral workforce needs in the United States, as well as to regional and state-level workforce discussions and activities. These efforts will be briefly discussed here.

At the national level, the *Annapolis Coalition on Behavioral Health Workforce* led a multi-phase process to create a national strategic plan for behavioral health workforce development. The plan was sponsored by all SAMHSA Centers (i.e., CMHS, CSAT, CSAP) and encompasses workforce issues for a comprehensive range of specialty areas (e.g., rural, co-occurring disorders). A major goal was to focus on common issues, while respecting the unique needs of each specialty area.

The results from the multi-phase process included the following: 1) broad national consensus on mission, vision, and strategic directions; 2) a proposed plan of action for SAMHSA and its federal partners; 3) a set of high priority interventions; 4) new or strengthened partnerships to implement the interventions; 5) focused action at the federal level; 6) focused action at the state and local levels; 7) focused action at the organizational level (providers, associations, educational); and 8) stimulate collective and individual action.

The phases of planning for development of the national strategy began at the start of 2005, with expert input from persons in recovery and their families, as well as specialists in the field, and consensus-building occurring from February to September, 2005. A draft plan was disseminated in early 2006, followed by public comment. The next step in developing the national strategic plan was to build on previous workforce initiatives and seek broad input from the field to identify a core set of strategic directions, specific, achievable goals, and a set of high priority _action_ items for strengthening the workforce. The final plan[6] is available on the Annapolis Coalition web site at: http://www.annapoliscoalition.org/national_strategic_planning.php.

In terms of regional efforts, in September, 2003, the Western Interstate Commission for Higher Education (WICHE) Mental Health Program convened a group of mental health directors, faculty and administrators from higher education institutions, policymakers, and other stakeholders in Reno, Nevada to engage in a discussion regarding supporting and enhancing a strong behavioral health workforce[7]. The basic premise of the meeting was that behavioral health and higher education can collaborate to develop effective workforce

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[6] Hoge, M. A., Morris, J. A., Daniels, A. S., Stuart, G. W., Huey, L. Y., & Adams, N. (2007). *An action plan on behavioral health workforce development.* Cincinnati, OH: The Annapolis Coalition on the Behavioral Health. (Available on-line at www.annapoliscoalition.org or at http://www.samhsa.gov/matrix2/matrix_workforce.aspx
[7] For more information on the WICHE Mental Health Program, please visit www.wiche.edu/mentalhealth

development strategies. This required a discussion of the multilevel contexts in which workforce shortages exist, the implications of these shortages, and possible solutions.

The Reno Meeting identified a number of factors and issues that confront behavioral workforce development in rural and frontier areas, including:

1. Components of a transformed rural and frontier mental health shortage initiative;
2. Strengths of the region;
3. Regional barriers/challenges; and
4. Academic Assets.[8]

Following the Reno Meeting the WICHE Mental Health Program received funding from SAMHSA to sponsor a second conference to bring together public behavioral health system and higher education stakeholders to continue the efforts of the Reno Meeting. The purpose of this follow-up meeting was to focus the discussion on behavioral health workforce issues in rural communities. "Building Partnerships in Rural Mental Health Workforce Development Meeting" was held in Mesa, Arizona in March 2005.[9] WICHE collaborated with the *Annapolis Coalition* to merge efforts and inform the national strategy on issues germane to rural behavioral health.

In terms of state-based initiatives, several states have recognized the need to examine and develop strategies to address behavioral health workforce issues. These initiatives have varied in, 1) scope (e.g., provider types included, target populations, etc.), 2) lead agency (e.g., state mental health department versus university driven), and 3) financial commitments (e.g., legislative funding, private foundation funds, public allocation of dollars). In the western region of the United States, the WICHE Mental Health Program (referenced above) has been involved in facilitating many of these strategic planning efforts at the state level including Alaska, Arizona, Nevada, North Dakota, New Mexico, Hawaii, and California. These state-based initiatives vary in breadth and stage of development depending on the priorities of the state and who is engaged in the discussion and planning.

Iowa's Behavioral Health Workforce

The national, regional, and state efforts currently underway indicate the presence of significant momentum behind behavioral health workforce development. These activities provide a context in which the State of Iowa can begin its own workforce development projects. Thus, this report is designed to present a picture of the current state of Iowa's behavioral health workforce in the context of relevant behavioral health topics. The information in the section below was compiled by reviewing a number of documents that included information pertinent to the status of behavioral health workforce in Iowa.

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[8] The "Reno Report" can be seen at http://ruralhealth.hrsa.gov/pub/WicheMH.asp
[9] The "Mesa Report" can be obtained by contacting WICHE directly at http://www.wiche.edu/mentalhealth

In 2000, Iowa was projected to be the 30th most populous state, with 2.9 million people[10]. However, **in 2000 Iowa ranked 47th among states in the number of psychiatrists per 100,000 people and 46th among states in the number of psychologists per 100,000 people**.[11]

A 2005/2006 survey assessed Iowa's mental health workforce. 46% of mental health entities responded to the survey (hospitals, mental health centers, state facilities, and private providers). There were a total of 280 budgeted vacancies for mental health workers across all settings, with 54% of the budgeted vacancies having been vacant for more than 60 days. The report concluded that "**… action is needed to avert a crisis in care**." (This document did not have identifiable source information but was titled "A Summary of Four Mental Health Workforce Surveys in Iowa.")

A 2005 report by the Center for Health Workforce Planning in the Bureau of Health Care Access in the Iowa Department of Public Health studied 24 Iowa health professions to identify and prioritize potential shortages[12]. 63% (15) projected more than 20 percent of their licensees to be age 55. Mental health professions exhibited the highest combined percentage of licensees age 55 and older. A summary of the report stated "**Iowa is likely to lose a considerable number of experienced mental health professionals in the next ten years due to retirement…. The anticipated retirement of large numbers of licensees will only exacerbate problems**."[13] The report identified six recommendations that are noted in Appendix C.

In 2006, the Center for Health Workforce Planning produced a report on *Iowa's Mental Health Workforce*. This report assessed the current professional-level mental health workforce in Iowa, and painted an initial picture of the challenges currently facing Iowa's mental health systems. The findings of this 2006 report are highlighted in the section below to provide an overview of the current state of Iowa's mental health workforce.

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[10] Iowa's Population Projections, U.S. Bureau of the Census, http://www.census.gov/population/projections/state/9525rank/iaprsrel.txt
[11] U.S. Department of Health and Human Services Bureau of Health Professions, 2000. The Iowa Health Workforce: Highlights from the Health Workforce Profile. Available at: http://bhpr.hrsa.gov/healthworkforce/reports/statesummaries/iowa.htm
[12] Center for Health Workforce Planning, Bureau of Health Care Access, Iowa Department of Public Health 2005 report: *A Report Prioritizing a Potential Shortage of Licensed Health Care Professionals in Iowa*.
[13] Center for Health Workforce Planning, Bureau of Health Care Access, Iowa Department of Public Health 2006 report: *Iowa's Mental Health Workforce*.

Current and Future Shortages in Iowa's Behavioral Health Workforce

In Iowa, 81 of 99 counties are designated as shortage areas in Mental Health Care HPSA catchment areas[14]. The map below shows these counties. Counties in white are counties without shortage area designations, counties in pink are counties pending de-designation, and counties in orange are designated shortage areas. As can be seen in the map, most Iowans live in areas with a severe shortage of mental health care workers. Given the severe shortage of mental health care workers in Iowa, it is not surprising that the state ranked 47th among states in psychiatrists per capita, 46th in psychologists per capita, and 28th in social workers per capita[15]. Additionally, there were more than 732 nurse practitioners in Iowa in 2000. This was equal to 25 nurse practitioners per 100,000, lower than the national rate of 33.7 per 100,000[16].

Mental Health Catchment Areas (MHCA)
as of October 31, 2005

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[14]Center for Health Workforce Planning, Bureau of Health Care Access, Iowa Department of Public Health 2006 report: *Iowa's Mental Health Workforce*.

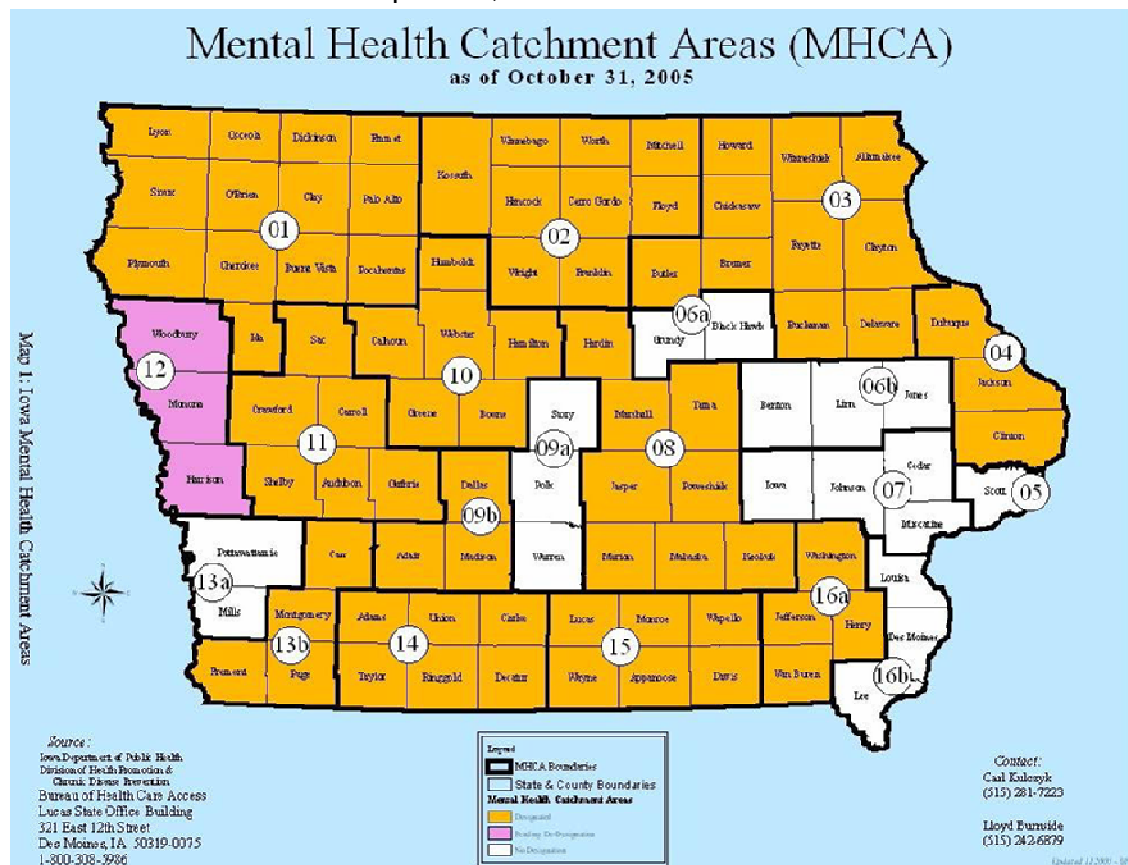[15] U.S. Department of Health and Human Services Bureau of Health Professions, 2000.The Iowa Health Workforce: Highlights from the Health Workforce Profile. Available at: http://bhpr.hrsa.gov/healthworkforce/reports/statesummaries/iowa.htm

[16]U.S. Department of Health and Human Services Bureau of Health Professions, 2000.The Iowa Health Workforce: Highlights from the Health Workforce Profile. Available at: http://bhpr.hrsa.gov/healthworkforce/reports/statesummaries/iowa.htm

The table below[17] shows comparative data for Iowa and its contiguous states.

I	Iowa	Illinois	Minnesota	Missouri	Nebraska	South Dakota	Wisconsin
Total: Physicians	4,527	24,300	9,500	10,500	2,900	1,280	10,170
State Ratio/100,000	155	195	194	188	171	169	189
National Ratio/100,000	198	198	198	198	198	198	198
National Rank	47	17	21	26	34	36	25
Total: Primary Physicians							
State Ratio/100,000	67	70	76	67	62	67	71
National Ratio/100,000	69	69	69	69	69	69	69
National Rank	NA						
Total: Psychiatrists	164	1,396	462	497	142	55	528
State Ratio/100,000	5.7	11.6	9.8	9.1	8.6	7.5	10.1
National Ratio/100,000	12.6	12.6	12.6	12.6	12.6	12.6	12.6
National Rank per capita	47	16	28	30	35	39	24
Total: Physician Assistants	412	1,349	711	395	356	90	1,070
State Ratio/100,000	14.1	10.8	14.4	7	20.8	11.9	19.9
National Ratio/100,000	14.4	14.4	14.4	14.4	14.4	14.4	14.4
National Rank per capital	NA						
Total: Advanced Practice	7,410	22,690	16,870	19,520	6,230	1,870	12,160
State Ratio/100,000	253	182.4	341.9	348.3	363.6	247.4	226.3
National Ratio/100,000	240.8	240.8	240.8	240.8	240.8	240.8	240.8
National Rank per capita	21	37	9	8	6	46	27
Total: Psychologist	560	5,430	2,950	1,540	410	110	2,910
State Ratio/100,000	19.1	43.6	59.8	27.5	23.9	14.6	54.1
National Ratio/100,000	36.2	36.2	36.2	36.2	36.2	36.2	36.2
National Rank per capita	46	13	5	30	39	47	7
Total: Social Workers	4,600	24,170	11,620	10,320	2,950	1,990	9,250
State Ratio/100,000	157.1	194.3	235.5	184.1	172.2	263.3	172.1
National Ratio/100,000	159.1	159.1	159.1	159.1	159.1	159.1	159.1
National Rank per capita	28	15	7	18	22	2	23
Total: Registered Nurse	35,000	126,000	54,900	62,400	18,500	9,600	58,650
Ratio/100,000	1,059.2	817.1	954.6	958.6	957.1	1,126.1	891.2
National Rank	NA						
National Ratio	780.2	780.2	780.2	780.2	780.2	780.2	780.2

Iowa's low ranking of several core mental health professions indicates that, for a number of years, mental health services have been provided with a minimal number of professionals. The anticipated retirement of large numbers of licensees will only exacerbate problems.[18]

Psychiatrists

Iowa is the state with the 47th lowest per-capita number of psychiatrists in the nation. As the following figure shows, the majority of mental health catchment areas in Iowa have fewer than 10 psychiatrists. Three catchment areas have no psychiatrists at all.

In May of 2005, there were 231 active psychiatrists in Iowa. 64% of those psychiatrists work in private practice, 17% work in a teaching/research position, 6% work in a state institution or agency, 5% work in public/community health, 4% work in a federal/veterans facility, and the remaining 4% work in another capacity.

The number of active psychiatrists in Iowa remained relatively constant between 1995 and 2005. However, in 2005, 35% of Iowa's active psychiatrists were 55 or older, which means Iowa may lose approximately 80 psychiatrists by 2015.

There are 472 actively licensed psychologists in Iowa, with 88% of those psychologists holding in-state licenses. Iowa does not require licenses from school psychologists; academic employees who teach, train, or conduct research; governmental employees; and students or interns. Therefore, the number of unlicensed psychologists in Iowa is unknown.

Psychologists

As the figure below demonstrates, the western and southern portions of the state have the greatest need for psychologists. Although there are licensed psychologists in every mental health catchment area, some only have one or two licensed psychologists.

Psychologists represent the group of healthcare workers in the state with the largest percentage of workers ages 55 or older. 47% of the psychologists in Iowa were 55 years of age or older in 2005, indicating that almost half of the psychologists in Iowa will reach retirement age by 2015.

Advanced Registered Nurse Practitioners (ARNPs)

Of the 1,219 ARNPs in Iowa, only 5% specialize in psychiatric/mental health services. This includes 23 mental health nurse practitioners, 7 child/adolescent psychiatry nurse practitioners, and 37 adult psychiatric nurse practitioners. The majority of ARNPs with mental health specialties work in private practice settings, with a psychiatrist or a psychologist, or in a private counseling center. As shown in the figure below, only one mental health catchment area in Iowa has more than 10 ARNPs with mental health specialties. Six mental health catchment areas have no ARNPs with mental health specialties. All but two of Iowa's mental health catchment areas have 5 or fewer ARNPs with mental health specialties.

Approximately 24% of ARNPs in Iowa will reach retirement age by 2015, indicating that the already high need for ARNPs with mental health specialties will become more pronounced over the next few years.

Social Workers

Social workers represent the largest group of mental health providers in Iowa. In 2005 there were 4,204 licensed social workers, with 93% of social workers holding in-state licenses. As the figure below indicates, there are only two mental health catchment areas with 10 or fewer social workers. The majority of mental health catchment areas have between 11 and 50 social workers.

Map 5: Social Workers

Social Workers Working in Mental Health Settings in Iowa
2005
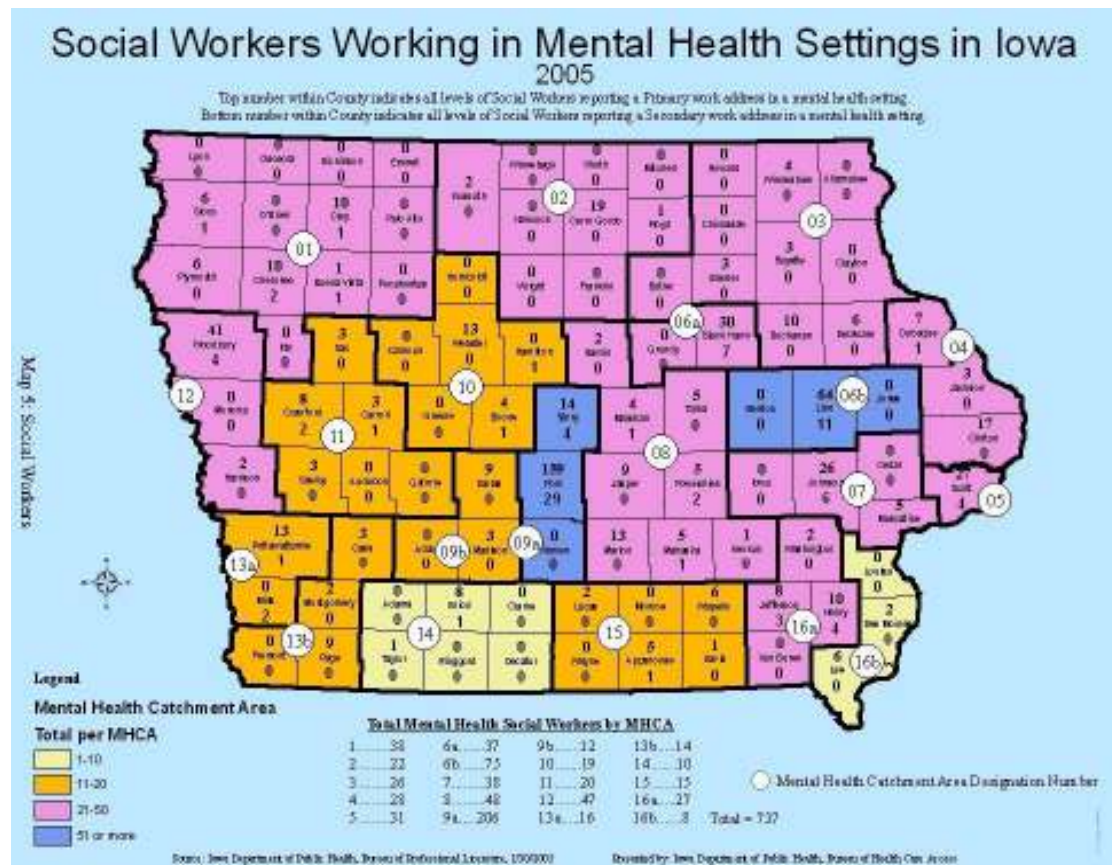
Twenty-eight percent of licensed social workers were age 55 or older in 2005. Between 2000 and 2005, 879 first-time licenses were issued for in-state social workers[19]. If current

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[19] Percentages do not total 100% due to rounding.

trends continue, there should be a sufficient number of licensed social workers to replace those who will retire from the Iowa workforce by 2015.

Marital & Family Therapists

In 2005, there were 157 licensed marital and family therapists in Iowa. As shown in the figure below, the majority of mental health catchment areas have fewer than 10 marital and family therapists, and three mental health catchment areas have no marital and family therapists. . Over the past 10 years, there has been a consistent decline in the number of marital and family therapists seeking licensure.
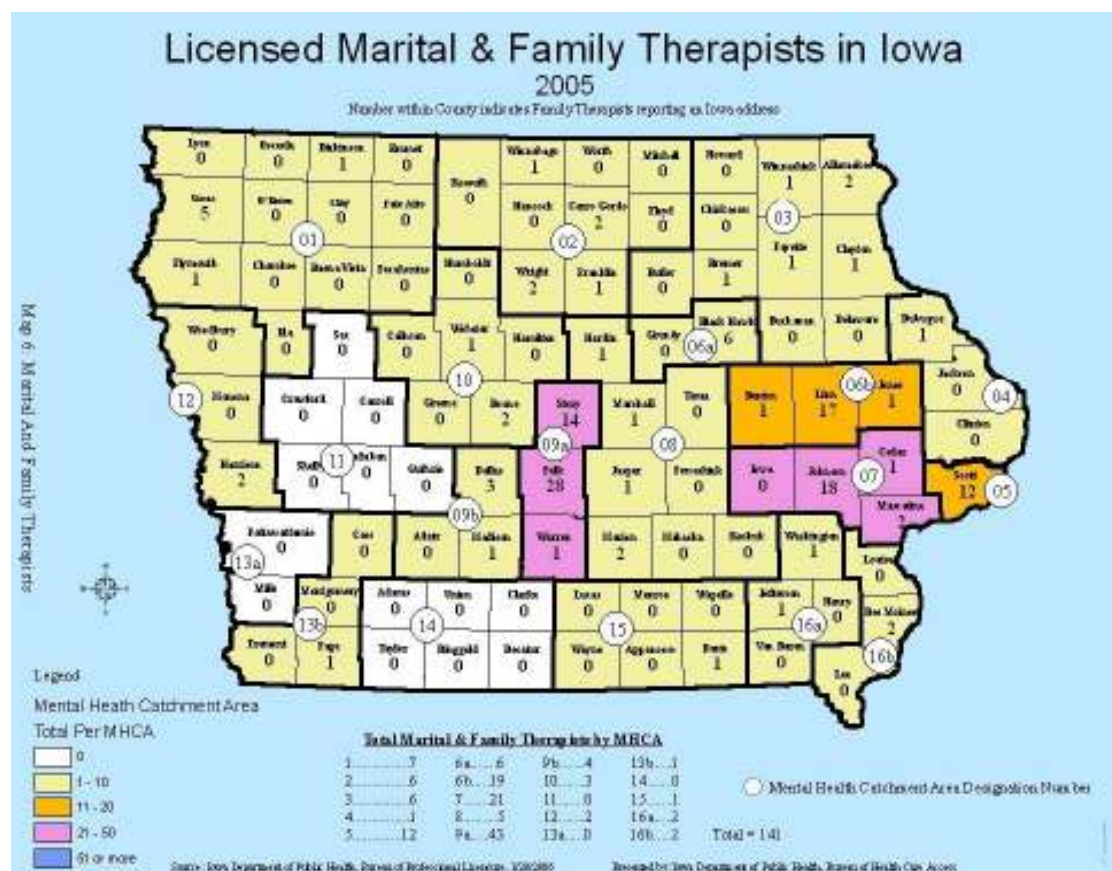
38% of the licensed marital and family therapists were age 55 and over in 2005, which means that Iowa will lose many of its marital and family therapists by 2015.

Physician Assistants

Physician Assistants work under physicians, and have prescribing privileges for some psychotropic drugs. Along with psychiatrists and ARNPs, they are the only mental health workers who have prescription privileges. As shown in the figure below, there are very few licensed physician assistants supervised by psychiatrists (those most likely to be providing mental health care). Most mental health catchment areas have no PAs, and only one mental health catchment area has as many as 10 PAs supervised by psychiatrists.

Map 7: Physician Assistants Supervised By Psychiatrists Licensed in Iowa 2005

Mental Health Counselors

There were 535 active mental health counselor licenses in 2005. Between 1996 and 2005, there was an average of 37 first-time mental health counselor licenses given out each year. In 2005, 34% of the licensed mental health counselors in Iowa were age 55 or older, indicating that there is a growing need for new mental health counselors in Iowa.

The figure below shows that most mental health catchment areas in Iowa have at least 10 licensed mental health counselors. However, there is a very uneven distribution of mental health counselors in the state, with almost 25% of mental health counselors concentrated in a single county (Polk County).
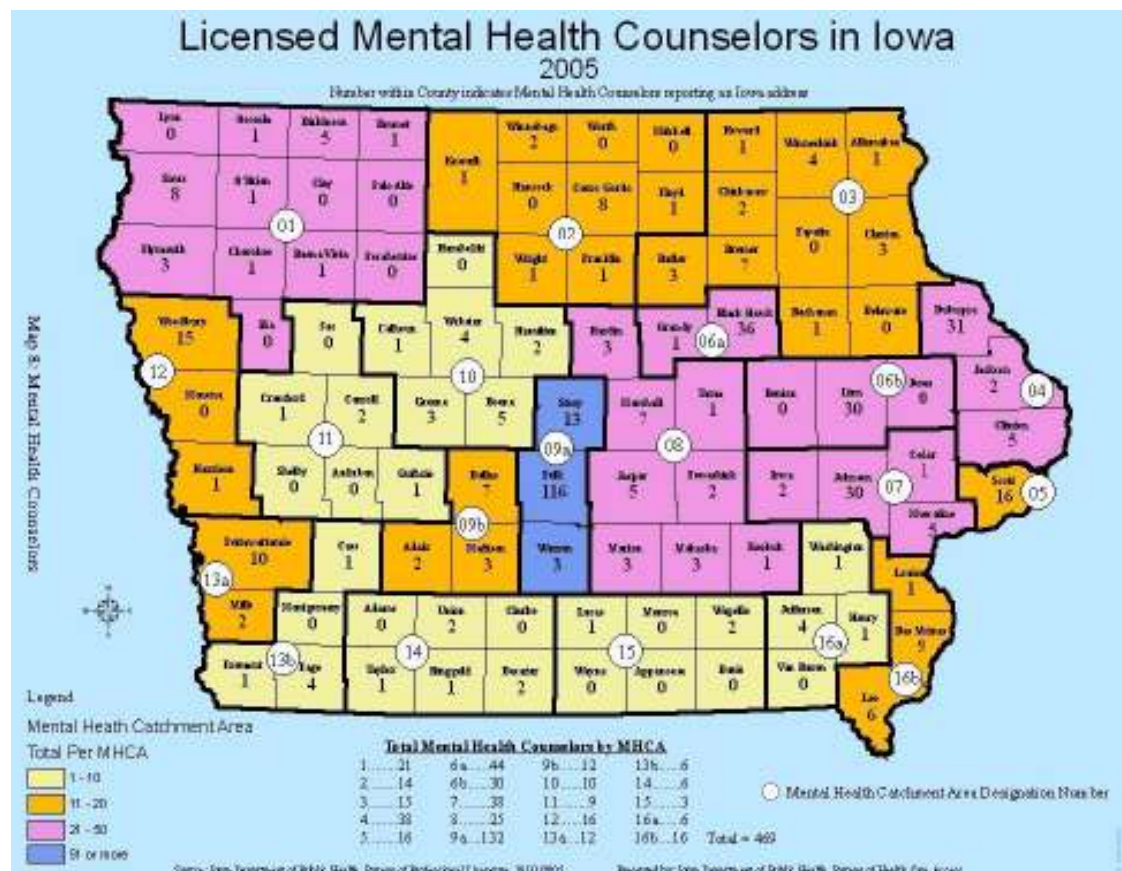
Source: Center for Health Workforce Planning Bureau of Health Care Access, Iowa Department of Public Health, *A Report Prioritizing a Potential Shortage of Licensed Health Care Professionals in Iowa*, May 2005, available at www: idph.state.ia.us/hpcdp/health_care_access.asp

WORKFORCE INFRASTRUCTURE

Creating a renewed and sustainable workforce will require a set of building blocks that must be methodically engineered to serve Iowa's unique needs. This is not a set of challenges for which there is a pre-packaged, off-the-shelf, one-size-fits-all solution.

These five elements have to be the drivers for whatever Iowa ultimately decides will be its workforce solutions:

1. **Training for Competencies**

   Toward this end, Iowa will have to:

   - Develop training programs designed around worker needs and mental health and disability practitioner competencies and priorities.
   - Develop a standard training program for consumers and families to prepare them to serve as trainers.

2. **Offering Comprehensive Evidence-based Training Programs**

   Using outdated or ineffective methods of training is just as fruitless as using outdated or erroneous information. Iowa must reorient its efforts to ensure that all trainees are learning in environments that foster *changed practitioner behavior*: To that end, Iowa must:

   - Promote and/or provide high-quality learning opportunities in accessible settings and formats in an "evidence-based" way.
   - Provide systematic, competency-based training programs for key mental health and disability transformation topics.
   - Develop and provide targeted educational initiatives related to the implementation of specific evidence-based practices such as Assertive Community Treatment, Integrated Dual Diagnosis Treatment, Supportive Housing, Illness Management and Recovery, Family Psychoeducation, etc.

3. **Building Systems that Support Practitioner Development and Career Ladders**

   If the system isn't modified to reinforce new knowledge and skills, it is unlikely that the new knowledge and improved skills will be sustained over time. Therefore Iowa's future system effort must:

   - Promote credentials and competency-based training requirements for mental health practitioners.

- Implement training and development of competency-based Supervisory skills.
- Seek partnerships with colleges/universities and other education providers to meet mutual practice and training needs of both mental health practitioners and students.

4. Building Systems/ Organizations that Support the Use of Evidence-based Practices

Scientific research in recent decades has radically altered our perception of how much independence, resilience, and recovery is possible for individuals with developmental and behavioral conditions. That research has to drive the way we practice and the types of supports and services we offer to Iowa's citizens. Our efforts going forward must reflect these changed expectations, and must:

- Support and model the values of mental health transformation towards the achievement of a recovery-oriented service delivery system that is consumer and family driven.
- Serve as a technical resource to state agencies, community-based organizations, consumers and recovery organizations.
- Coordinate existing resources to focus on and leverage training for implementation efforts.

5. Disseminating Current Mental Health Practice Research.

With the explosion of research on the causes, course, and treatments for developmental and behavioral conditions, it is virtually impossible for clinicians and service providers to remain current in their knowledge. Iowa must prepare a range of strategies designed to reach out assertively to providers, and to ensure that the state can:

- Provide current and state-of-the art treatment practice information and resources through specialized publications, web-based information, and the use of Telebehavioralheath and Teletraining.
- Provide coordinated and targeted technical assistance to Iowa's provider community to ensure that policy infrastructure modifications are made to ensure that improved practices can be financed and delivered statewide.

In its work with the State of Iowa, the Annapolis Coalition has recommended two concrete strategies: the creation of a Mental Health and Disability Services (MHDS) Center for Clinical Competence and Training Institute (CCCTI) , and the creation of an Iowa Behavioral Health Workforce Collaborative to advise and guide the development and

evolution of the CCCTI. We describe each concept briefly here, and revisit these recommendations later in this report.

Development of the Mental Health and Disability Services Center for Clinical Competence and Training Institute

In the winter of 2006 and spring of 2007, the Iowa Department of Human Services (IDHS), Division of Mental Health and Disability Services (MHDS), in collaboration with the state legislature, embarked upon a Mental Health Systems Improvement (MHSI) initiative that included a number of workgroups focusing on systems change. One workgroup focused on evidence-based practices. In 2007, the Iowa legislature (HF909) directed the IDHS to:

> **"develop a comprehensive training program concerning such practices for community mental health centers, state resource centers and mental health institutes, and other providers, in collaboration with the Iowa Consortium for Mental Health."**

In the summer of 2007, the MHDS began a planning process that included the Iowa Consortium for Mental Health, the Center for Disabilities Development, the Iowa College of Public Health, the University of South Florida Mental Health Institute, ZiaPartners, Inc., and the Annapolis Coalition to form the Mental Health and Disability Services Center for Clinical Competence and Training Institute (MHDSCCCTI). That planning process sought to respond to the legislative mandate to develop a comprehensive training program as stated above.

Also during the summer of 2007 other workgroups were meeting with MHDS that included various stakeholders such as providers, county representative, family members, consumers and advocacy groups. Guided by expert technical advisors such as the Annapolis Coalition and the Iowa Consortium for Mental Health a plan evolved for the creation of the MHDSCCCTI. The MHDSCCCTI was envisioned as a center for evidence-based training on mental health and disability issues for professional and direct care staff providers, family, consumers, including DHS mental health institutes, resource centers, community mental health centers and other community substance abuse and mental health providers. Specific provider populations initially targeted by the MHDSCCCTI were those offering co-occurring mental health and substance abuse disorder services, as well as those providing emergency mental health, children's mental health, and school mental health services.

Iowa is in the process of transforming its publicly funded mental health system to a consumer and family-driven system that embraces prevention, resiliency, and recovery as guiding principles. Implementing that goal requires shedding old stereotypes of mental illness and replacing them with new attitudes and services that support people with mental illnesses. In the midst of this transition, the mental health system faces a crisis in providing

appropriate mental health services to forensic clients. Without systematic and quality training as well as attention to effective strategies needed for implementation of new practices, the realization of Iowa's transformation goals could be compromised.

This initiative will require dedicated in-state staff and resources to ensure that all relevant partners are included, and that the efforts to develop Iowa's capacities are a constant focus of attention.

Creating a Workforce Collaborative

Essential to the success of a statewide effort of this type is an infrastructure to identify and prioritize workforce problems, coordinate or implement interventions, and monitor outcomes. Perhaps most important, an infrastructure is necessary to link and leverage *existing* resources that are available within the state to strengthen its workforce.

The functions of such an infrastructure would include, but not be limited to the following:

Leveraging existing resources by:
- Identifying and disseminating information about existing workforce development resources (clearinghouse function).
- Coordinating workforce development efforts among various public and private agencies to achieve efficiencies and reduce duplication of effort.

Linking Iowa's mental health and higher education systems in a coordinated effort to develop a pipeline of culturally diverse and appropriately trained mental health providers. This includes:
- Educating educators about current trends in service delivery as a strategy for fostering relevant curricula in the educational system
- Working with the mental health, higher education, licensing systems, and payers to improve career ladders in mental health within Iowa.

Assessing routinely the mental health workforce development needs within Iowa, including:
- The magnitude, characteristics, and causes, of recruitment and retention problems, including the impact of compensation and benefits
- The accessibility, relevance, and effectiveness of training and education resources/program.

Planning in the form of a biannual strategic plan on mental health workforce development and report on the status of this workforce will be conducted by the Collaborative.

Implementing interventions to strengthen the workforce.

Promoting employment of consumers, youth, and family members in the mental health workforce.

Disseminating best practices in workforce development to employers of the mental health workforce.

Advising Iowa's executive, legislative, and judicial branches on workforce issues and policy.

Applying for other potential sources of funds to support workforce development.

The structure of the Collaborative would include a General Membership, Executive Committee, Standing Councils, and ad hoc workgroups.

Persons in recovery, youth, and the parents of children and youth with emotional and mental problems would play a major role in all structures.

Technology, in the form of web-enabled conference calls, will be used for selected meetings to maximize efficiency, minimize time and travel-related meeting costs, and foster access for consumers and family members.

The collaborative can serve as the **Advisory Council** to the CCCTI

, ensuring that the voices of key stakeholders are heard, and that all elements of the system are engaged in the selection, design, delivery and evaluation of the work of the Institute. The Collaborative sets the policy direction for the work of the Institute in strengthening Iowa's workforce.

The activities of the Collaborative would be the responsibility of the Project Director identified above in the Basic Infrastructure section; the Institute would staff the work of the Collaborative and provide its administrative home.

HIGHER EDUCATION

In order to meet the current and future unmet needs of those with behavioral health problems, a large number of professional positions in behavioral health need to be filled. Additionally, those trained to become behavioral health clinicians require exposure to behavioral health issues facing rural residents, as well as issues inherent in the public mental health system (e.g., Medicaid). Higher education behavioral health programs are a logical and important part of achieving these goals.

Recent research by the National Center for Public Policy and Higher Education suggests that demographic changes to the country's population could lead to decreases in high school and college diplomas, as well as personal income in the next 15 years.[20] Specifically, there are projected to be "substantial increases in America's young population with the lowest level of education, combined with the coming retirement of the baby boomers—the most highly educated generation in U.S. history..." (p. 1). Additionally, data indicates ongoing disparities among various racial/ethnic groups regarding education achievement. Approximately 47% of Hispanics/Latinos have less than a high school credential, and only 16% have an Associate's degree or higher. With the working-age minority population in Iowa projected to grow to 9% by 2020[3], these discrepancies in education will become even more apparent.

Table 1: Iowa Racial and Ethnic Gaps in Educational Levels of Working-Age Population (ages 25-64), 2000[21]

	Whites	Hispanics/Latinos
Less than a high school credential	8%	47%
Associate's degree or higher	34%	16%

Iowa ranks 4th in the nation in high school graduation rates, and 6th in 6-year graduation rates of students in bachelors degree programs. However, in the 5 years preceding the

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[20] http://www.highereducation.org/reports/pa_decline/index.shtml
[21] National Center for Public Policy and Higher Education,
http://measuringup.highereducation.org/reports/stateProfileNet.cfm?myYear=2006&statename=Iowa&cat=AI

2000 census, Iowa had a net negative migration of adults ages 22-29 with associate's degrees or higher[22].

Although Iowa ranks among the top five states in the nation for importing first-time freshmen to 4-year colleges/universities, it ranks in the bottom 30% of states retaining young college graduates (ages 22-29) [3]. One issue Iowa will need to overcome to ensure an adequately trained workforce is retaining its college-educated population.

According to the National Center for Public Policy and Higher Education, strengths and weaknesses in Iowa's higher education system include[23]:

Strengths

Preparation

- Eighth graders perform well on national assessments in math and reading.
- Very large proportions of high school students enroll in upper-level math and science courses. The proportion enrolled in upper-level science has increased substantially over the past 12 years, and Iowa has shown some of the greatest improvement among states on this measure. Iowa is a top-performing state in the percentage of secondary school students taught by teachers with an undergraduate or graduate major in the subject they are teaching.

Participation

- Iowa is among the leading states in the chance that a 9th grader will enroll in college within four years. Iowa has consistently been a top performer on this measure. However, the state's performance has declined over the past decade, primarily due to a decline in the percentage of 9th graders graduating from high school in four years.

Completion

- Iowa has consistently performed very well on the percentage of freshmen at four-year colleges and universities returning for their sophomore year. However, this percentage has declined substantially over the past 15 years.

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[22] The Emerging Policy Triangle: Economic Development, Workforce Development, and Education, http://www.wiche.edu/policy/Ford/EPT_May2007.pdf
[23] National Center for Public Policy and Higher Education, http://measuringup.highereducation.org/reports/stateProfileNet.cfm?myYear=2006&statename=Iowa&cat=AI

- Iowa has consistently been a top performer on the proportion of students completing certificates and degrees relative to the number enrolled. However, the state has declined on this measure over the past 12 years, in contrast to a nationwide increase.

Weaknesses

Preparation

- Very low proportions of 11th and 12th graders take and score well on Advanced Placement tests.
- Among 18- to 24-year-olds, non-whites are two-thirds as likely as whites to earn a high school credential.

Affordability

- Net college costs for low- and middle-income students to attend public two- and four-year colleges represent 39% and 45% of their annual family income, respectively. (Net college costs equal tuition, room, and board after financial aid.) These two sectors enroll 69% of college students in the state.
- Iowa makes a very low investment in need-based financial aid compared with leading states, and offers no low-tuition college opportunities.

Iowa Higher Education Behavioral Health Programs

Iowa has three public universities: the University of Iowa, Iowa State University, and the University of Northern Iowa. There are 15 community college districts, with 2 districts having multiple campuses (Eastern Iowa Community College District and Iowa Valley Community College District). Iowa has one public medical school for psychiatry training: the University of Iowa. In addition, there are two public universities that offer doctoral-level psychology training: the University of Iowa and Iowa State University. The University of Iowa College of Nursing offers the only training program for advanced registered nurse practitioners who wish to specialize in psychiatry. The University of Iowa and the University of Northern Iowa both offer master's degree level social work training, as well as undergraduate programs in social work. The University of Iowa's Department of Human Development and Family Science offers master level and doctoral level programs in marital and family therapy. Physician assistants can acquire master level training at the University of Iowa, and mental health counselors can obtain Masters of Science or Masters of Arts degrees from all three Iowa public universities.

Psychiatrists[24]

Of the active psychiatrists in Iowa, 36% received their degree from an Iowa university, 36% received their degree from out of state (mainly Illinois and Nebraska), and 28% received their degree from another country (mainly India and Pakistan).

Between 1996 and 2005, only 9 psychiatrists graduated from the University of Iowa (with only 2 graduates between 2001 and 2005). The University of Iowa provides the only residency program for psychiatrists in the state, but between 1996 and 2005, 97 psychiatrists graduated from the University of Iowa's residency program (between 7-12 graduates per year). Although Iowa universities are not graduating many doctors whose training focuses on psychiatry, Iowa is educating enough psychiatric residents to replace those who will be retiring over the next few years. However, only 36% of the psychiatrists who completed their residencies between 1996 and 2005 remained in Iowa, indicating that a majority of Iowa-trained residents are being employed by other states or countries.

Recommendations

- Resident Retention. With so few Iowa medical students focusing on psychiatry, the state would increase their chances of retaining psychiatrists by focusing on residents rather than medical students. With only one option for residency placement in psychiatry, medical students interested in pursuing psychiatry who graduate from one of Iowa's two medical schools are likely to find residencies out-of-state. This out-of-state placement is often a better option than a residency position at the medical school from which the students graduated, as it provides more breadth in training and exposure to different models and theories for treatment.
- Loan Repayment. Residents might be encouraged to remain in Iowa following graduation and psychiatry medical students might be encouraged to return if there was a financial incentive for doing so. According to the American Association of Medical Colleges, the average educational debt of the 87% of 2006 graduates who carried outstanding loans was $130,571. In addition, 40% of 2006 graduates had non-educational debt, averaging $16,689. One way to increase the number of Iowa psychiatrists might be to offer loan repayment programs to offset some of their accrued educational debt.
- Rural-Focused Training Opportunities. Iowa needs to offer rural-focused residency opportunities, which provide much needed exposure and training in rural mental health issues. The University of New Mexico Center for Rural Community and Behavioral Health instituted the Rural Psychiatry and

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[24] These data and figures were taken from the Center for Health Workforce Planning, Bureau of Health Care Access, Iowa Department of Public Health 2006 report: *Iowa's Mental Health Workforce*.

Behavioral Health Training Program[25] to provide continued and increased opportunity for rural residency rotations in adult, child, geriatric and addictions fellowship programs; and to offer an opportunity for the development and integration of a rural interdisciplinary behavioral health training rotation(s) in other fields: psychology, social work, nursing, and physicians assistants. In this program, rural track residents spend one to two days/week for 6 months to a year in designated sites throughout New Mexico. Possible rotations are in Primary Care Sites as well as Community Mental Health Centers, with training sites in numerous predominantly Native American and/or Hispanic communities throughout the state. Rotations are funded through the New Mexico Department Human Services, Behavioral Health Services Division and the New Mexico Children, Youth and Families Department, and focus on topics such as: direct care, services research, mental health policy, Native American behavioral health programs, and program evaluation.

Psychologists[26]

Doctoral programs in psychology provide the only training opportunities leading to licensure. In Iowa, there are two universities that offer doctoral programs in Psychology: the University of Iowa, and Iowa State University. Both programs offer clinical psychology training, but their goal is to train clinical psychologists for scholarly work, rather than clinical work. This is particularly true for the University of Iowa[27].

158 of the 168 graduates from these two universities were tracked between 1995 and 2005. 18% of the psychologists who graduated during this period of time began employment in Iowa, but the most frequent placements were in academic rather than clinical jobs. Even if all 18% of the psychologists who graduated from Iowa universities between 1995 and 2005 took clinical jobs in Iowa, only 28 Iowa-educated psychologists would have joined the Iowa mental health workforce over those 10 years. With 250 licensed psychologists approaching retirement age, and so few Iowa-educated psychologists taking clinical jobs in Iowa, there is clearly a great need for doctoral-level psychologists in Iowa.

Recommendations

- Increase Internship Opportunities. Psychologists must complete pre-doctoral internships as a part of their graduate training. However, there are only 3 sites in Iowa that offer accredited internship programs: the University of Iowa

[25] http://hsc.unm.edu/som/Psychiatry/crcbh/rural.shtml
[26] These data and figures were taken from the Center for Health Workforce Planning, Bureau of Health Care Access, Iowa Department of Public Health 2006 report, *Iowa's Mental Health Workforce*.
[27] http://www.psychology.uiowa.edu/grad.html

Counseling Service, the Iowa Sate University Student Counseling Service, and the VA Central Iowa Health Care System in Knoxville[28]. This lack of internship training sites in the state decreases Iowa's opportunities to bring in and retain out-of-state psychologists, as well as to retain psychology Ph.D. graduates. In 2007, over 30% of psychology students were not matched for an internship program, although only 10% of internship programs failed to get a psychology intern[29]. Even if some of the unmatched students later took internships in the 10% of programs without interns, there were still 546 students who did not obtain internships in 2007. By adding more internships sites, particularly in rural areas, Iowa could capitalize on the overabundance of well-trained psychologists to supplement its mental health workforce.

- PsyD Program. One possible solution to Iowa's psychologist shortage would be to offer a PsyD program at one of the public universities. In contrast to PhD programs, PsyD programs train psychologists to be practitioners rather than scientists. PsyD programs typically enroll three times the number of doctoral students that PhD programs enroll, although PsyD programs offer less financial aid[30]. Another way to increase the number of licensed psychologists in Iowa would be to offer more opportunities for internships. Bringing in psychologists from out-of-state may increase the likelihood that the psychologists will become licensed in Iowa. Iowa's current internship options include only one hospital, and two university student health clinics. Offering internship opportunities in other hospital or clinic locations, particularly in rural areas, would likely bring more licensed psychologists to Iowa communities.

Advanced Registered Nurse Practitioners (ARNPs)[31]

The University of Iowa College of Nursing offers the only program in the state that provides training for advanced registered nurse practitioners specializing in mental health. This program was revised in 1999 to meet national requirements for certification to enable psychiatric nurses to become licensed as ARNPs. The first class from this modified program graduated in 2001, and the program has graduated 9 psychiatric/mental health nurses. All but one of these nurses currently practice in Iowa.

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[28] American Psychological Association Office of Program Consultation and Accreditation, http://www.apa.org/ed/accreditation/interni.html
[29] 2007 Association of Psychology Postdoctoral and Internship Centers Match Statistics, http://www.appic.org/match/5_2_2_1_9_match_about_statistics_general_2007.html
[30] Mayne, T. J., Norcross, J. C., & Sayette, M. A. (1994). Admission requirements, acceptance rates, and financial assistance in clinical psychology programs: Diversity across the practice-research continuum. *American Psychologist, 49*, 806-811.
[31] These data and figures were taken from the Center for Health Workforce Planning, Bureau of Health Care Access, Iowa Department of Public Health 2006 report, *Iowa's Mental Health Workforce*.

Recommendations

- Increase Distance Learning Opportunities. The psychiatric training program at the University of Iowa College of Nursing is geared toward practicing psychiatric nurses throughout the state. One way to increase the number of ARNPs with psychiatric specialties would be to offer distance learning options for practicing psychiatric nurses. If the course work could be completed online, practicing nurses could work toward certification from their homes during off hours, without having to travel or interrupt their workdays. This transition to an online, web-based format for course work would be particularly helpful in increasing the number of ARNPs with mental health specialties in rural areas, which are located furthest from the University of Iowa's psychiatric training program.

Social Workers[32]

The University of Iowa and the University of Northern Iowa are the only public institutions offering accredited master level social work programs in Iowa. Both universities also offer baccalaureate programs. The University of Iowa is the only institution in Iowa offering a Ph.D. program in social work.

One-third of the new social work licenses granted in Iowa were to social workers who graduated from out-of-state institutions. Thus, Iowa is doing a good job of recruiting as well as retaining social workers.

Recommendations

- Communication Across Disciplines. The directors of the social work programs at the University of Iowa and the University of Northern Iowa may have useful advice for other Iowa mental health education programs on how to recruit and retain students (particularly for the psychiatry residency program at the University of Iowa, which brings in a large number of psychiatrists, but is not effective in retaining its graduates).

Marital & Family Therapists[33]

There is a master's and PhD degree program for marital and family therapy at the University of Iowa's Department of Human Development and Family Science. However, only two currently licensed marital and family therapists had degrees from Iowa institutions.

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[32] These data and figures were taken from the Center for Health Workforce Planning, Bureau of Health Care Access, Iowa Department of Public Health 2006 report, *Iowa's Mental Health Workforce*.
[33] These data and figures were taken from the Center for Health Workforce Planning, Bureau of Health Care Access, Iowa Department of Public Health 2006 report, *Iowa's Mental Health Workforce*.

Recommendations

- Increase Enrollment. The University of Iowa will need to increase the enrollment of students in its marital and family therapy program, and retain its graduates, in order to build up its licensed marital and family therapist workforce.

Physician Assistants (PAs)[34]

There is only one approved physician assistant program at a public university in Iowa. The University of Iowa awards a certificate of completion, as well as a Master of PA studies. At least 58% of first-time PA licenses given between 2001 and 2005 went to individuals who received their degrees from another state.

Given that there is only one program in the state for training physician assistants, Iowa must rely heavily on recruitment in order to develop a sufficient physician assistant workforce. Recruitment is particularly important in the area of mental health, which has a very low number of licensed physician assistants.

Mental Health Counselors[35]

All three public universities offer Master of Science or Master of Arts degrees in mental health counseling. Between 2000 and 2005, these three universities graduated 56 mental health counselors. During that same period of time, 121 mental health counselors received their professional degree from an out-of-state university.

Peer Support Specialists

The role of peers in supporting one another is rapidly being recognized as a promising direction for systems of care. Given the special dimensions of this element of the workforce, it is addressed in a special section below.

Summary

With a large proportion of Iowa's mental health workforce approaching retirement age during the next few years, it is imperative that Iowa educate and recruit a sufficient mental health workforce to meet the state's mental health demands. Iowa's psychiatrist and psychologist workforces are particularly in danger of shortages, as in-state training opportunities for those professions are especially limited. To determine the educational needs of Iowa's mental health workforce, it is imperative that representatives from the state,

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[34] These data and figures were taken from the Center for Health Workforce Planning, Bureau of Health Care Access, Iowa Department of Public Health 2006 report, *Iowa's Mental Health Workforce*.
[35] These data and figures were taken from the Center for Health Workforce Planning, Bureau of Health Care Access, Iowa Department of Public Health 2006 report, *Iowa's Mental Health Workforce*.

higher education, and mental health workers come together to discuss solutions to the state's shortage of mental health workers.

The shortages of mental health workers in Iowa are seen most acutely in rural areas of the state. Mental health professionals across all levels tend to reside and work in metropolitan areas, leaving rural areas in large need of mental health services. One solution to this problem is to make greater use of paraprofessionals to provide mental health services to rural populations. Alaska has recently implemented a certificate program for training paraprofessionals, whereby students meet for 1-3 weeks of intensive course work each semester to work toward an Associate of Applied Sciences Human Services degree. The certificate program could be implemented in online courses through Iowa's community college network. Each of Iowa's 15 community college districts offers distance learning options through online courses. These distance learning options may be ideal for rural individuals interested in becoming mental health service providers without having to travel large distances to attend courses.

The 2006 Iowa Department of Public Health report on *Iowa's Mental Health Workforce* offered the following additional recommendations for improving Iowa's mental health workforce.

1. That the Bureau of Professional Licensure and the Office of Statewide Clinical Education Programs combine efforts to gather and report detailed employment information about mental health professionals working in Iowa.

2. That the Bureau of Professional Licensure continues their efforts to activate an on-line licensure renewal process in order to facilitate collection and reporting of employment and education information.

3. That education programs and professional organizations determine ways and means to recruit and retain more students into mental health professions.

4. That education programs provide to as many students as possible, ease of access to mental health curriculums and continuing education updates through the use of e-learning.

5. That legislators determine ways to provide incentives such as loan repayments to graduates and new hire assistance to potential employers of Iowa mental health graduates who practice in the state.

6. That professional associations assist in developing a working definition of what constitutes a "shortage" in their profession that includes, but is not limited to, budgeted vacancies.

7. That licensure boards review the scope of practice, educational requirements including internships, licensure procurement processes, and procedures for endorsement of out-of-state licensees in order to facilitate timely entry into practice.

8. That citizen groups use the data to inform their constituents and make recommendations to legislators.

9. That practice and education develop collaboratives that expand local opportunities for clinical experiences leading to licensure and/or certification.

10. That health professionals and associations promote awareness among employers regarding competencies, prescribing authority and reimbursement issues impacting advanced registered nurse practitioners, physician assistants, and other mental health professionals.

11. That health professions explore practice models that improve the quality and efficiency of mental health services.

PEER SUPPORTS

There has been a sea change in the world of mental conditions in the past decade. Persons in recovery (and their families) have increasingly been recognized as integral parts of the intervention, treatment and supports for each other, In fact, in the Annapolis Coalition *Action Plan for Behavioral Health Workforce Development* peers are seen as potentially transformative contributors to workforce reform. In its policy statement on peer supports, Mental Health America (a national advocacy organization, formerly known as the Mental Health Association), clearly endorses the role as part of any effective system of care.

In the substance use conditions field, the role of peers in recovery is well established, and is the foundation of the twelve-step movement represented by Alcoholics Anonymous, Narcotics Anonymous, etc.

This recognition of the patient/client/consumer/participant[36] as driving his- or her own care is not unique to behavioral and development conditions, but is consistent with general medical care, as reflected in the work of the Institute of Medicine, which has called for "patient-centered care"[37].

Iowa has begun to adopt this practice, and has already trained a number of Certified Peer Specialists; these are individuals who have completed a state-approved training curriculum and who are credentialed to provide a specific scope of services. In many states, these services are billable under the state Medicaid plan or through a behavioral health "carve out" operated by a behavioral health managed care organization.

In addition to the individual or group services provided by Certified Peer Specialists, many states are supporting peer-operated services such as warm-lines, drop in centers, and respite centers. Research into the effectiveness of peer-operated services has validated their important role in a comprehensive array of services and supports for persons with mental and substance use conditions. In Appendix B we provide an annotated bibliography on consumer operated services prepared by Campbell *et al*.

In a state with such critical shortages in specialist providers, broad use of peer supports seems an especially attractive strategy to improve access to recovery and resilience oriented supports.

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[36] Persons in recovery have various terms by which they prefer to be identified.

[37] Institute of Medicine (2006) Committee on Crossing the Quality Chasm: Adaptation to Mental Health and Addictive Disorders. *Improving the Quality of Healthcare for mental and substance-use conditions.* National Academy of Sciences, The National Academies Press, 599 Fifth Street, NW, Washington, DC..

DIRECT CARE WORKFORCE

Statement of the Problem[38]

About 12.3 million people deliver healthcare services in the United States. Almost 5 million of these providers are "frontline workforce" and numbers of front line workforce are estimated to increase by 50% by the year 2012. They are typically educated at or below the bachelor's degree level and are often referred to as "direct care" or "paraprofessional" employees. Direct care job titles include, mental health counselor, psychiatric nurse, substance abuse and behavioral disorder counselor, psychiatric aide, and psychiatric technician. Some states may use different labels for these positions and the scope of job duties vary. These workers provide a large portion of direct care and information to consumers and are often the first point of contact for people initiating care. They provide prevention and screening, rehabilitative care, long term care, and a host of other crucial services. Despite the importance of direct care to mental health care, these employees receive relatively little attention, especially in terms of research. They earn low wages, have limited access to benefits, receive little or no formal training, and must rely largely on peers and trial and error for their education. Supervision is not offered at regular intervals and employees are not provided with formal competencies and certification processes. They have very little access to advancement and rewards in general. It's no surprise that as a result direct care employees often feel undervalued in their workplaces.

A skilled and stable direct care workforce is essential to the provision of quality mental health care. Yet, often the working conditions deny direct care workers what research has found to be some the most basic components of job satisfaction, such as opportunities to grow and advance, a living wage, and health care benefits.[39] This results in numerous problems in recruiting and retaining direct care workers.

Recommendations

Recruitment, retention, and training and education of direct care workers are related issues and could work synergistically to strengthen this key component of the Iowa mental health workforce. Recommendations made (also in this report) for recruitment and retention of professionals (e.g., psychiatrist, etc.) should be carried out for paraprofessionals as well.

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[38] From an article on the Robert Wood Johnson Foundation Website entitled *Frontline Workforce Development*: *Promoting Partnerships and Emerging Practices in Health and Health Care* which can be found at http://www.rwjf.org/programareas/resources/product.jsp?id=20902&pid=1135&gsa=1

[39] From *An Action Plan for Behavioral Health Workforce* which was commissioned by the Substance Abuse and Mental Health Services Administration and is available at http://www.annapoliscoalition.org/files/Strategic_Planning/WorkforceActionPlan.pdf

These recommendations are described in greater detail in the section on recruitment and retention of professional mental health workforce. However, to summarize:

- Wages and benefits must be commensurate with work responsibilities and a living wage must be provided to employees.

- Provider organizations must be informed of and must employ evidence-based recruitment and retention practices.

- A public relations campaign should be launched to recruit people into the mental health workforce.

- Creation of a web portal for students, employees, and employers as a way to increase communication between and across direct care employers and professionals (i.e., job listings, training opportunities, etc.).

- Implementation of "grow your own" strategies

In addition to these recommendations, the following strategies might be carried out as well:

- Iowa should consider initiating the development of direct care competencies, accessible training, and a career ladders for current and future mental health direct care employees. The state of Alaska has initiated several programs which can provide a model and a starting point for Iowa. These programs are unique because they increase access to education, skill building, and career advancement with on the job training and by training workforce largely in their own communities. These programs are summarized below.

- Jobs to Careers[40]
  The focus of this project is workplace learning and career development for direct care behavioral health workers in rural Alaska. The Alaska's Jobs to Careers Project has strong commitments from four organizations with established expertise in building strong workforces in rural mental health. These are: 1) University of Alaska at Fairbanks Alaska Rural Behavioral Health Training Academy (ARBHTA), 2) Norton Sound Health Corporation (NSHC), 3) the Annapolis Coalition on the Behavioral Health Workforce, and 4) the Western Interstate Commission for Higher Education (WICHE) Mental Health Program. The project clarifies the competencies required for these workers, improves the career ladder by linking training

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[40] For more information on the broader efforts of the Jobs to Careers Program, which is funded by the Robert Wood Johnson Foundation, go to http://www.jobs2careers.org/

opportunities to academic credit, assesses and plans for the individualized needs of workers, and designs and implements a work-based learning model for the state of Alaska.

- University of Alaska Behavioral Health Certificates and Degrees[41]
  In rural and frontier Alaska, the root network the health services system is a collective of local paraprofessionals. University of Alaska at Fairbanks, through its College of Rural Alaska, has developed a successful and progressive education pathway which enables Alaska to educate its own culturally competent behavioral health providers. The first priority of this program is to empower local residents and natural practitioners of culture as the professional behavioral health workforce. Building on the ever present and successful paraprofessional network, Alaska Natives and other rural residents can now advance, if they choose, seamlessly from a one year certificate (30-34 university credits) program through bachelor's degrees in social work, psychology, human services, and rural development. The education of these behavioral health employees includes web-based learning, audio conferences and other technologies that make educational advancement more accessible because they reduce the cost of education and allow students to be educated largely in their own communities. Brief but intensive courses are provided on Alaska college campuses as well. Within the University of Alaska system, this educational pathway extends through masters degrees in either social work or rural development (see appendix A for a visual aide regarding this program).

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[41] More information on this program can be found at www.uaf.edu/crahealth

RECRUITMENT AND RETENTION

Recruitment, Retention, and Training and Education of Direct Care Workforce

Statement of the Problem.[42] About 12.3 million people deliver healthcare services in the United States. Almost 5 million of these providers are "frontline workforce" and numbers of front line workforce are estimated to increase by 50% by the year 2012. They are typically educated at or below the bachelor's degree level and are often referred to as "direct care" or "paraprofessional" employees. Direct care job titles include, mental health counselor, psychiatric nurse, substance abuse and behavioral disorder counselor, psychiatric aide, and psychiatric technician. Some states may use different labels for these positions and the scope of job duties vary. These workers provide a large portion of direct care and information to consumers and are often the first point of contact for people initiating care. They provide prevention and screening, rehabilitative care, long term care, and a host of other crucial services. Despite the importance of direct care to mental health care, these employees receive relatively little attention, especially in terms of research. They earn low wages, have limited access to benefits, receive little or no formal training, and must rely largely on peers and trial and error for their education. Supervision is not offered at regular intervals and employees are not provided with formal competencies and certification processes. They have very little access to advancement and rewards in general. It's no surprise that as a result direct care employees often feel undervalued in their workplaces.

A skilled and stable direct care workforce is essential to the provision of quality mental health care. Yet, often the working conditions deny direct care workers what research has found to be some the most basic components of job satisfaction, such as opportunities to grow and advance, a living wage, and health care benefits.[43] This results in numerous problems in recruiting and retaining direct care workers.

Recommendations

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[42] From an article on the Robert Wood Johnson Foundation Website entitled *Frontline Workforce Development*: *Promoting Partnerships and Emerging Practices in Health and Health Care* which can be found at http://www.rwjf.org/programareas/resources/product.jsp?id=20902&pid=1135&gsa=1
[43] From *An Action Plan for Behavioral Health Workforce* which was commissioned by the Substance Abuse and Mental Health Services Administration and is available at http://www.annapoliscoalition.org/files/Strategic_Planning/WorkforceActionPlan.pdf

These recommendations are described in greater detail in the section on recruitment and retention of professional mental health workforce. However, to summarize:

- Wages and benefits must be commensurate with work responsibilities and a living wage must be provided to employees.

- Provider organizations must be informed of and must employ evidence-based recruitment and retention practices.

- A public relations campaign should be launched to recruit people into the mental health workforce.

- Creation of a web portal for students, employees, and employers as a way to increase communication between and across direct care employers and professionals (i.e., job listings, training opportunities, etc.).

- Implementation of "grow your own" strategies

In addition to these recommendations, the following strategies might be carried out as well:

- Iowa should consider initiating the development of direct care competencies, accessible training, and a career ladders for current and future mental health direct care employees. The state of Alaska has initiated several programs which can provide a model and a starting point for Iowa. These programs are unique because they increase access to education, skill building, and career advancement with on the job training and by training workforce largely in their own communities. These programs are summarized below.

Jobs to Careers[44]

The focus of this project is workplace learning and career development for direct care behavioral health workers in rural Alaska. The Alaska's Jobs to Careers Project has strong commitments from four organizations with established expertise in building strong workforces in rural mental health. These are: 1) University of Alaska at Fairbanks Alaska Rural Behavioral Health Training Academy (ARBHTA), 2) Norton Sound Health Corporation (NSHC), 3) the Annapolis Coalition on the Behavioral Health Workforce, and 4) the Western Interstate Commission for Higher Education (WICHE) Mental Health Program. The project clarifies the competencies required for these workers, improves the career ladder by linking training opportunities to academic credit, assesses and plans for the individualized needs of

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[44] For more information on the broader efforts of the Jobs to Careers Program, which is funded by the Robert Wood Johnson Foundation, go to http://www.jobs2careers.org/

workers, and designs and implements a work-based learning model for the state of Alaska.

University of Alaska Behavioral Health Certificates and Degrees[45]

In rural and frontier Alaska, the root network the health services system is a collective of local paraprofessionals. University of Alaska at Fairbanks, through its College of Rural Alaska, has developed a successful and progressive education pathway which enables Alaska to educate its own culturally competent behavioral health providers. The first priority of this program is to empower local residents and natural practitioners of culture as the professional behavioral health workforce. Building on the ever present and successful paraprofessional network, Alaska Natives and other rural residents can now advance, if they choose, seamlessly from a one year certificate (30-34 university credits) program through bachelor's degrees in social work, psychology, human services, and rural development. The education of these behavioral health employees includes web-based learning, audio conferences and other technologies that make educational advancement more accessible because they reduce the cost of education and allow students to be educated largely in their own communities. Brief but intensive courses are provided on Alaska college campuses as well. Within the University of Alaska system, this educational pathway extends through masters degrees in either social work or rural development (see appendix A for a visual aide regarding this program).

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[45] More information on this program can be found at www.uaf.edu/crahealth

TRAINING AND EDUCATION

One of the main foci of training and education (which here explicitly references continuing education and on-the-job training) is the development of a workforce that is capable of bringing the best scientific knowledge about effective intervention and services to Iowa's citizens; this is generally referred to as the movement toward evidence-based practices (EBPs)[46]. There has to be a laser-like focus on *competencies*, which will also drive strategies to ensure that practitioners actually modify their practice behaviors, that systems are modified to support changing practices, and that supervisors and leaders understand the complexity of managing such a changed system—a significant and daunting set of tasks.

We are cognizant of the fact that the rural nature of much of Iowa poses special challenges for implementing many of the more widely recognized, manualized evidence-based interventions. Therefore, Iowa will also need to create structures to evaluate modifications of standardized practices, but also to assess the effectiveness of current practice—what is often referred to as "practice-based evidence.

In terms of recognized practices, Iowa has made significant gains. This work has evolved through four phases of activity[47].

Four Phases:

Phase I: "EBP Project 1"

2001-2002: An initial project was funded by the Mental Health Planning Council to review the status of the use of EBP's in Iowa and make recommendations A Request for Proposals (RFP) was issued using Mental Health block grant funding: It was awarded to Iowa Consortium for Mental Health (ICMH) in collaboration with State Public Policy Group (SPPG).

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[46] Hyde, PS, Falls, K, Morris, JA, and Schoenwald, SK. (2003). *Turning Knowledge into Practice: A Manual for Behavioral Health Administrators and Practitioner about Understanding and Implementing Evidence-Based Practices.* The Technical Assistance Center & The American College of Mental Health Administration, 535 Boylston Street, Ste 1301, Boston, MA 02116.

[47] This portion of the report summarizes some of Iowa's initiatives in investigating, disseminating and implementing evidence-based practices within its publicly funded mental health system. It is admittedly from the perspective of one organization – the Iowa Consortium for Mental Health (ICMH) – and must be taken in that context. However, it is probably fair to say the ICMH has been the most active group in pursuing and providing leadership in this area.

The ICMH Evidence-Based Practices Project 1 identified a set of goals to shape its work. These goals included:

- Review the literature on EBP's in mental health
- Describe selected EBP's, according to multiple parameters
- Look at use of EBP's in Iowa, as compared to elsewhere
- Identify barriers to implementation
- Package results in a digestible form for dissemination to a variety of stakeholders, including policy makers

In order to achieve its goals, ICMH gathered a multidisciplinary, stakeholder group to do the literature review, and survey of practices around the state.

The results of this phase of work were documented in a report entitled: Moving Towards Best Practices. That document, which was widely disseminated to a variety of stakeholders, found the following:

- There are a number of accepted mental health practices that have a solid evidence base; these are detailed in the report.
- Most of these practices are targeted towards adults with severe and persistent mental illnesses;
- These EBPs are being under-utilized in Iowa;
- There are innovative practices going on throughout the state, which should be further studied to determine if there exists or can be created an evidence base for their efficacy.
- Resources should be dedicated to enhancing implementation and ongoing evaluation of all evidence-based and promising practices;
- There is a need for increased awareness and consensus building among stakeholders about the use EBP's. This is a necessary next step.

Following this report, a variety of grant applications were generated to follow-up on this initial work, leading to Phase II.

Phase II 2002 – 2004 : Technical Assistance Center for Evidence Based Practices

The formation of a "Technical Assistance Center for Evidence-Based Practices" was funded through Community Reinvestment dollars from Magellan Behavioral Health, and allocated to ICMH as part of Phase II.

The projects were Initially funded in 2003 via Medicaid dollars (community reinvestment funds from the Medicaid managed care Mental health/Substance Abuse services carve-out).

Two Technical Assistance divisions were selected, focusing on 2 of the 6 SAMHSA endorsed "toolkit" EBPs for adults. The two selected were:

- Assertive Community Treatment (ACT)
- Illness Management and Recovery. (The name was changed to "Wellness Management and Recovery – or WMR)

Each was treated as a separate project, the ACT-TAC and WRM-TAC. Because of their different focus, the goals were very different for the two practices.

Goals and work of ACT-TAC:

- Increase awareness and understanding of ACT in Iowa.
- Assemble a statewide advisory board.
- Propose a sustainable funding model for ACT in Iowa.
- Conduct fidelity reviews of ACT teams.
- Develop Iowa specific ACT program standards.
- Assess and support the educational needs of Iowa ACT teams.
- Standardize and aggregate outcome measures across Iowa ACT teams.
- Develop interest in potential ACT sites
- Bring up two new ACT teams (within a 2 year period, expanding the number from 3 to 5 statewide)

Progress on ACT goals

- Essentially all goals were achieved over the following 2 year period.
- 2 new ACT programs developed and brought up.
- Existing programs strengthened
- Expense of the technical assistance was significant - ~ $200K for years 2003-2004, scaled back to ~ $100K thereafter – still continuing.

Goals of WMR TAC

- Enhance dialogue and understanding of the recovery construct within the broad mental health community
- Provide a forum for various recovery-oriented groups within Iowa to come together with the goal of "speaking in one voice"
- Assess recovery-orientation of CMHC's
- Pilot IMR toolkits
- Promote WRAP – Wellness Recovery Action Plan

Progress on WMR TAC goals

- Significant progress towards each of these goals were made
- Statewide multi-stakeholder group convened and met on an ongoing basis, bringing together many different recovery-oriented consumer-led organizations, together with providers
- IMR toolkit piloted in 2 clinical sites
- WRAP trainings conducted in 3 sites / year
- Level II WRAP trainings – i.e., "train the trainer" established and conducted
- Recovery assessments conducted at multiple CMHC's, using structured tools
- Sponsored numerous conferences with recovery-oriented themes

Phase III: 2004-2007: "Legislative Mandate requiring Mental Health block grant funds to be used for EBPs.

Partly as a result of the various efforts at enhancing dialog and understanding of EBP's among stakeholders statewide, legislation was passed in 2004 requiring that 70% of Iowa's Mental Health Block grant be used to enhance the implementation of EBP's in Iowa's CMHC's. This was to go into effect July 1, 2005. The following timetable reflects the progress made:

- Spring 2004: DHS and the mental health planning council issued an RFP to assist in implementing this mandate
    - ICMH was the only bidder, and was awarded the contract (renewable for 5 years, currently in its 4th year
- Fall 2004: Statewide dissemination: ICMH hosted a 7 part series on EBP's for adults with serious and persistent mental illnesses, broadcast throughout the state via the Iowa Communications Network. Average attendance ~ 450 / session across ~ 60 sites statewide.
- Summer 2004 – Spring 2005: ICMH convened a multi-stakeholder planning and advisory group to help determine methods to implement this EBP mandate
- Spring 2005: Information disseminated to all CMHC's on how EBP's would be defined, assessed and reviewed within the block grant funding through conference and written materials, summarized below.
    - A new application and review process created and implemented
    - Emphasis on practicing in an "evidence-based manner" with a focus on enhancing clarity of intervention, documentation of outcomes, and quality improvement.
- Fall 2005: ICMH hosts statewide series on EBP's for children with SED's, also through ICN; widely attended.
- 2006 – 2007: CMHC's implement above with varying degrees of success and resistance
    - "Interest groups" developed in 6 areas, 3 for adults with SMI, and 3 for Children with SED

- Biannual meetings in which all interest group participants are brought together peer-to-peer learning and networking
- ICMH works closely with DHS staff to provide technical assistance to all participants and review progress on a quarterly basis, including outcome data.

Phase IV: EBP's within the Mental Health System Improvement Plan: 2007-2008

- Spring 2007: As per legislation in 2007 session, DHS agrees to pursue mental health system improvement plan, one aspect of which involves recommendations on enhancing EBP's.
- Summer 2007: Multi-stakeholder workgroup convened and meets regularly, generating recommendations for broader implementation of EBP's for adults with SMI and children with SED's (far beyond scope of block grant).
- Fall 2007: EBP workgroup report submitted to legislature with recommendations for broader implementation of EBP's.

This foundational work on evidence-based practices reflects Iowa's commitment to using science to drive practice. In numerous interviews conducted in preparation of this report, representatives of the Annapolis Coalition and the Mental Health Program of the Western Interstate Commission for Higher Education heard that both inadequate numbers of trained workers and their distribution throughout the state created major challenges for further elaboration and development of system wide use of EBPs.

WEB-BASED TRAINING AND TELEHEALTH

Telemedicine & Telehealth

Telemedicine and telehealth networks are a valuable resource especially for geographically rural states like Iowa. Telemedicine[48] is a part of telehealth, just as telemental health, telepsychiatry, and telepharmacy are also components of telehealth. *Telehealth[49]*, a broader, more encompassing term than telemedicine and therefore, will be used in this section of the report. The use of technology to transmit health information from one location to another has evolved to remove geography and transportation barriers to care. Such technology enables patients to receive care in their own communities who otherwise might not have access to care. Telemedicine can be beneficial in addressing capacity issues (i.e., availability of providers) in a rural state mental health system. If the telehealth network is created and utilized efficiently, providers (e.g., psychiatrists) can even contract for the provision of services across different systems (e.g., corrections, mental health agencies, etc.).

Telemedicine: the use of electronic communication and information technologies to provide or support clinical care at a distance[1].

Telehealth: the use of electronic information and telecommunications technologies to support long-distance clinical health care, patient and professional training and education, and health administration[2].

Telehealth does not necessarily create new services but rather, provides an alternative way to deliver existing services. Telehealth networks can be used to support and enhance current clinical service delivery capacity, including such functions as clinical assessment/diagnosis, crisis stabilization, medication management, 24/7 psychiatric consultation, and pre- and post-hospitalization services. In addition, telehealth networks can be maximized to include distance training and education for providers in small rural clinics across the state. Training (i.e., for continuing medical education or continuing education credits) provided on site via distance networks helps offset the inconvenience and cost associated with travel to larger venues. In some rural states, telehealth networks have been used to provide supervision from a distance when geography impedes doing face-to-face meetings.

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[48] 1997, Telemedicine Report to Congress, U.S. Department of Commerce, P.1.
[49] 2001, Telemedicine Report to Congress, U.S. Department of Health and Human Services, P.13.

Some identified benefits of introducing telehealth (i.e., telemental health/telepsychiatry) services into a mental health care delivery system include:

- Improved access to care;
- Provision of a higher level of care locally or in a more timely fashion;
- Timely medication management;
- Improved continuity and coordination of care;
- Family involvement;
- Improved treatment compliance; and
- Cost savings for patients (i.e., for travel and lost wages)[50].

The history of telehealth applications began around 1955, when the Nebraska Psychiatric Institute began using closed circuit TV to monitor patients remotely. A 2007 report by the Center for Information Technology Leadership states that since the mid-fifties, telehealth has been adopted slowly due to a variety of barriers, which were identified across several resources, including: 1) a lack of clinical evidence and financial value of these technologies; 2) a perception that the increase in access to care will lead to large increases in the cost to pay for that care; 3) a current reimbursement model that favors face-to-face visits; 4) concerns around medical liability; and 5) a lack of cross-state licensure to provide such services[51].

Over the past 10 years the technologies needed to provide healthcare services at a distance have vastly improved and drastically dropped in price; reimbursement for telehealth is more broadly available than it was 10 years ago; and the cost of

telecommunication services in many areas is much lower thanks to competition and the Federal Communication Commission's Rural Health Care Support Mechanism (i.e., universal service fund), which provides discounts for telecommunications services provided by eligible rural healthcare facilities using telehealth technologies[52].

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50 Telemedicine Technical Assistance Documents: A guide to getting started in Telemedicine; Joseph Tracy, MS, Dena Puskin ScD 2004 Chapter 9 Mental Health Authors: Thelma McClosky Armstrong, MA, Rob Sprang,
51 Center for Information Technology Leadership, 2007. The Value of Provider-to-Provider Telehealth Technologies. Caitlin M. Cusack, MD, MPH; Eric Pan, MD, MSc; Julie M. Hook, MA, MPH; Adam Vincent, MPP; David C. Kaelber, MD, PhD; David W. Bates, MD, MSc; Blackford Middleton, MD, MPH, MSc
52 Iowa Department of Public Health Center for Health Workforce Planning, 2006. Planning and Training for a Telehealth Workforce for Rural Iowa: A Project Conducted by the Child Health Specialty Clinics, Iowa City, Iowa.

Current Telehealth Activities in Iowa

When preparing this report, we received one document from August, 2006 (Planning and Training for a Telehealth Workforce for Rural Iowa[5]) outlining the telehealth activities of the Child Health Specialty Clinics. There are likely other telehealth projects that exist in the state, however, this is the only effort that was included in the documents we reviewed. It should be noted that the efforts of the CHSC target their efforts to serving children and their families. A more comprehensive approach in terms of target populations is recommended for Iowa, however, this section will provide some background on what is occurring in telehealth in the child arena and is relevant to implementing a broader approach. The information in this section is taken from the report referenced above.

The number and location of health practitioners in Iowa, the number of patients served, and the types of services should be documented and analyzed on a regular basis.

Robust data collection will help identify areas of need in order to plan for appropriate enhancements in telehealth services.

Due to statewide professional shortages, securing the services of pediatricians, especially child psychiatrists, presents a special challenge in Iowa. Since 2003, Child Health Specialty Clinics (CHSC) has been using a statewide telehealth/telepsychiatry program as a way to provide care for children with special health needs, especially, although not exclusively, in the area of behavioral health. This program provides specialty healthcare in rural areas where there has historically been a shortage of specialty providers (e.g., pediatricians and child psychiatrists).

While some anecdotal reports of telehealth efforts in Iowa exist, the CHSC report indicated that it has been very difficult to determine the amount of telehealth activity across the state as a whole. The Iowa Hospital Association does not have any specific data regarding which hospitals are utilizing telemedicine and for what patients or specialties. The Iowa Department of Public Health, in collaboration with other medical organizations, maintains data on the number and location of health practitioners in the state. It would be useful if this data could be analyzed on a regular basis in order to determine the need for increased telehealth services. Regional CHSC clinics also keep data on the patients they serve and the types of services they provide. A regular analysis of this information will make it possible to identify areas of need and plan for appropriate additions or enhancements of telehealth services in those areas.

A Telehealth Training Manual was developed to train health professionals in the effective use of telehealth technologies. These materials were piloted in August of 2006 with medical

providers who would soon begin to use telehealth technology. The training manual can be used in its entirety or as individual modules.

Regarding the sustainability of telehealth, the report stated the following:

> *In order for telehealth to continue to be sustainable and effective, there needs to be a commitment on the part of the state of Iowa that this is a viable and valued method for addressing the shortage of subspecialty physical and behavioral health professionals in rural parts of the state. This commitment can come in the form of appropriations to support the technology infrastructure and in assurances that third party payments will continue to be available for medical services provided in this way. A billing issue that might be addressed is the inability to bill for both the physician at one telehealth site and the nurse or nurse practitioner who must be at the remote site with the patient. Under current policies, there is no way to bill for the time of the nurse who is present with the patient.*

As a way to educate legislators, CHSC invited the Chair and the Ranking Member of the Human Service Appropriations Committee to observe telehealth sessions and to discuss telehealth activities. The legislators were able to observe actual evaluations of children in which community-based providers were also present. The legislators commented on the value they saw to the families of having the presence of these local providers during the evaluation. The legislators also had the opportunity to discuss the clinicians experience with telehealth and their thoughts and observations regarding this method of delivery of services. Legislators had questions regarding the technology used, the cost of the system, what providers saw as the pros and cons of the service, and numbers of children served. They indicated that the information they obtained during the visit will be of value to them as they look at policy and funding issues during the legislative session.

CHSC conducted a survey of a few of the telehealth projects in Iowa (not all of which are still operating) and inquired about the factors important to their sustainability and success. These "success" characteristics are listed below:

- Financial resources necessary to purchase or enhance their telecommunications infrastructure and to put the organizational processes in place to support the system.
- Relatively self-contained systems that allow a great deal of control over record-keeping processes and billing processes.
- Organizational structure in place to assure that best practices are followed, and their system has the means to assure that providers have a high level of expertise in their subspecialty area.
- CHSC is noted as an example of this type of system that has the capacity and the expertise to provide telehealth services on a state-wide basis.

The CHSC report detailed a set of five general recommendations to move the telehealth system forward in the state of Iowa which are available in Appendix _A_. The document also included seven strategic steps to create a statewide system of specialty services for children available through telehealth technology. The report recommended conducting a regional pilot approach including the identification of needs of providers (e.g., availability

and capacity) and patients (e.g., prevalence and unmet need) across regions which would then lead to a region by region development and roll-out of the telehealth system. In addition to the general recommendations and the strategic steps, the report also suggested an approach for identifying the need and appropriate workforce projections (i.e., how many providers are needed for what services). This is also referenced in Appendix _A_.

Model Programs & Resources
The section below, while not an exhaustive list, briefly describes some programs and resources that may be useful when planning, implementing and funding a telehealth system in Iowa.

The Veteran's Administration (VA) is a national leader of systemic telehealth implementation. The VA recognizes that it is critical that telehealth be applied within the clinical, technical and business processes involved in the delivery of care. The VA developed a Telemental Health Toolkit in 2003 which is accessible at the following web address: http://www.va.gov/occ/toolkits/telementalhealth/vha_telemental_health_toolkit_06-22-03.pdf

The Eastern Montana Telemedicine Network (EMTN) began as a cooperative effort between the Billings Clinic and five rural healthcare facilities in eastern Montana to research the potential of interactive videoconferencing in improving access to medical specialty and mental health services. Today EMTN has 26 partners in 19 communities throughout eastern and central Montana and northern Wyoming. Since 1993, EMTN continues to utilize two way interactive video conferencing technology to deliver specialist medical and mental health services, continuing medical and higher education, administrative, and business services. In regard to mental health, EMTN provides the following services: medication review, follow-up visits to monitor patient progress, discharge planning, individual and family therapy, emergency consultation, patient care conferences, and employee assistance program.

The Office for the Advancement of Telehealth located in the Health Resources and Services Administration (HRSA) offers information about grant programs, best practices in telehealth, technical assistance documents, links to other telehealth resources, and relevant policy-related information regarding telehealth.
http://www.va.gov/occ/toolkits/telementalhealth/vha_telemental_health_toolkit_06-22-03.pdf

The United States Department of Agriculture (USDA) has a page devoted to telemedicine and telehealth resources including information on best practices, planning tools, funding resources, and general assistance through federal and state programs and/or organizations.
http://ric.nal.usda.gov/nal_display/index.php?info_center=5&tax_level=3&tax_subject=211&topic_id=1157&level3_id=5749

The American Telemedicine Association (ATA) was established in 1993 and is a non-profit organization headquartered in Washington, DC. ATA is a resource clearinghouse for telemedical information. ATA promotes access to medical care for consumers and health professionals via telecommunications technology.. ATA also publishes the *Telemedicine and e-Health Journal*. http://www.americantelemed.org/about/aboutH.htm

Recommendations

There are multiple paths to creating a telehealth network that meet the needs of the providers and consumers of services within a given system of care. Several steps would be important in order to initiate and implement a (or augment the existing) telehealth network in Iowa. These steps would need to be incorporated with the current activities of the Child Health Specialty Clinics as to not duplicate efforts.

- An assessment of the existing technology (e.g., equipment, transmission speed) in Iowa to establish a baseline of technological capacity throughout the state.
- A discussion regarding the intended use of the telehealth network, including scope of services, target population, clinical needs, and intended outcomes, to inform and direct the building of a new system or enhance the existing system.
- An analysis of how telemedicine/telehealth services are currently financed (e.g., is reimbursement of services provided through video technology included in the Iowa Medicaid plan?). Identification of how other states are reimbursed for technology-based services and interventions would be useful as well.
- A readiness assessment of provider understanding of, willingness, and capacity to participate in enhancing services via technology.
- An analysis of how privacy, confidentiality, informed consent, and recording the clinical encounter will be addressed.
- An analysis of how the system can be maximized for use outside of traditional purposes (e.g., clinical supervision, meetings and communication between agencies, training and continuing education).
- Participating networked sites need to have access to ongoing technical information, training, and support to ensure that the system can provide the intended services and maintain the equipment.
- Identify resources (e.g., state funds, private or federal grants) to support the sustainability of the network.

SPECIAL TOPICS IN IOWA THAT REQUIRE UNIQUE ATTENTION

Improved EBP Services for Children, Adolescents and Their Families

This is already an identified high priority for Iowa MHDS, and this funding would ensure that there are resources available to the system to support dissemination of evidence-based strategies. Funds would provide for the engagement of experts in identified best practices and for implementation of training sessions and development of fidelity monitoring technologies to ensure that practices are implemented in a way that is consistent with the scientific findings that drive the practice.

Improved Emergency Mental Health Crisis Services

Iowa's hospitals are struggling to meet the demands of persons with mental and developmental disorders in crisis, many of whom could be served both more effectively and in a more cost-effective manner by robust crisis and emergency mental health services, including such strategies as "Mental Health First Aid", peer supports, crisis prevention intervention, use of telephone "hotlines", and the like. Funding would provide for the engagement of key Iowa stakeholders, content experts in model design, and provision of basic training in new approaches to emergency mental health crisis services.

A comprehensive community-based crisis system with a broad and robust continuum of services, increases the likelihood that services will be the least intensive, intrusive and expensive necessary to effectively treat the person. Urgent appointments, the use of observation beds, and enhanced community-based resources assure that hospitalization is the resource of last resort.

Successful crisis systems require attention to all phases of the crisis continuum (including prevention, early intervention, acute intervention, treatment, and post-crisis reintegration/recovery) and the system and care provider competencies required for each. The ability to self-manage a crisis is a crucial component of recovery, and direct, ongoing care providers, including paraprofessionals, are in the best position to assist consumers in crisis prevention and early intervention. The direct care providers who are competent in this area are able to guide persons in treatment to creating treatment and crisis plans that are skill-building in nature, that identify and mitigate risks and that can be utilized effectively when a crisis does occur.

Hospitalization, particularly when involuntary, is costly in many ways. Certainly the hospital and professional fees are expensive as are the indirect costs to law enforcement and the court system. There is often a substantial cost to the person in recovery—a risk of job loss,

housing disruption, treatment disruption, relationship stress, as well as a lessened belief in one's own ability to recover.

The most effective crisis systems focus on upstream solutions—creating opportunities for mitigation of risk as soon as possible and before too much damage has been done. Effective prevention, a wide array of options for timely and effective early interventions and brief diversion services are essential elements of a recovery-oriented crisis system.

Community systems often collide in the midst of crisis episodes—and collision is often the best description. At a time of high clinical or behavioral acuity, law enforcement entities, courts, jails, child protective services may clash over the proper course of intervention. There is considerable opportunity for inter-system collaboration in the area of emergency mental health crisis services that will mitigate risks for all parties, right-size the use of resources like hospital or treatment beds, and streamline access to treatment.

RURAL WORKFORCE STRATEGIES

Rural Workforce Shortages

Workforce shortages are amplified in rural areas and often create disparities in health care not found in urban areas. While there is no one definition of "rural," there is a reality to the idea of distinct "rural cultures." For example, the needs of a rural community in Iowa will likely be different when compared to the needs of rural communities in Montana or Alaska. Availability of providers along the professional spectrum is limited in rural areas for a variety of reasons including geography (i.e. distance to the nearest provider), lack of transportation options, and lack of an economic draw for providers. Rural workforce strategies involve two primary aspects: 1) development of the existing workforce and 2) expansion of the workforce through recruitment and retention activities.

Approximately 85% of 1,669 federally designated Mental Health Professional Shortage Areas are rural[53]. The National Advisory Committee on Rural Health noted that across the 3,075 counties in the United States, 55% had no practicing psychiatrists, psychologists, or social workers, and *all* of these counties were rural. The National Advisory Committee on Rural Health reported that the supply of psychiatrists is about 14.6 per 100,000 people in urban areas compared to 3.9 per 100,000 in rural areas[54]. 90% of all psychologists and psychiatrists, and 80% of MSWs, work in metropolitan areas. Similar shortages exist for other behavioral health professions as well, such as social work and counseling. It is estimated that 65% of rural Americans get their mental health care from their primary care provider. In addition, rural Americans enter care later in the course of their disorders, with more advanced symptoms, resulting in more intensive & expensive interventions[55].

The ratio of behavioral health providers to the population worsens as rurality increases. Holzer and colleagues studied the availability of health and mental health providers by population density.[56] They found that only about 10% of frontier[57] counties had psychiatrists

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[53] Bird, D.C., Dempsey, P., & Hartley, D. (2001). *Addressing mental health workforce needs in underserved rural area: Accomplishments and challenges.* Portland, ME: Maine Rural Health Research Center, Muskie Institute, University of Southern Maine.

[54] National Advisory Committee on Rural Health. (1993) & (2004). *Sixth annual report on rural health.* Rockville, MD: Office of Rural Health Policy, Health Resources and Services Administration, HHS.

[55] New Freedom Commission on Mental Health. *Subcommittee of Rural Issues: Background Paper*. DHHS Pub. No. SMA-04-3890. Rockville, MD: 2004.

[56] Holzer, C.E. III, Goldsmith, H.F., & Ciarlo, J.A. (2000). The availability of health and mental health providers by population density. *Journal of the Washington Academy of Sciences* , 86 (3), 25-33.

[57] The definition of "frontier" is based on that of the Frontier Mental Health Services Resource Network, which is a county with less than 7 persons per square mile (it is slightly altered to be 2 to 6.9 persons per square mile, to include the categorization "very frontier").

and less than 1% of very frontier[58] counties had any psychiatrists. These rates of psychiatrists per 100,000 people for frontier and very frontier counties are 1.3 and 0.1, respectively. Additionally, only 13.3% of very frontier counties had psychologists (13 per 100,000), although frontier counties had 43.1% (18.1 per 100,000). For very frontier counties, 18.5% had social workers (12.8 per 100,000), while 23.4% exist in frontier counties (9.1 per 100,000). These data show the strong trend of sharply declining ratios of behavioral providers to populations as one gets farther away from urban areas.

There are multiple challenges to recruit and retain individuals in rural settings. Often, the strategy employed is to recruit urban-trained individuals to move to rural places. However, they are often reticent to move to rural communities for longer than a selected period (e.g., duration of loan repayment placement). In general, rural communities offer lower than standard wages and salaries in a field (i.e., mental health) that already offers wages that are quite low. Once individuals are placed in rural environments, there is often limited access to ongoing training and supervision, mentorship, and peer support.

Behavioral health workforce policy has been focused almost exclusively on doctoral-level providers (i.e., psychiatrists and psychologists). Social service agencies in rural areas across the country are generally staffed by a range of non-doctoral level providers, and typically do not formally adhere to any consistent standards of care or core behavioral health competencies. Staffing has been primarily influenced by State practice regulations and insurance reimbursement regulations than by science or competency[59].

Thirty-seven Iowa counties are part of core based statistical areas. Core based statistical areas include one or more counties comprised of core urban areas and adjacent counties with a high degree of social and economic integration.[60] In Iowa, 20 counties are included in metropolitan areas (core urban area of 50,000 or more population), and 17 counties are included in micropolitan areas (core urban area of between 10,000 and 50,000 population).[61] The remaining 62 counties in Iowa are considered noncore counties (i.e., population less than 10,000, including adjacent counties). Combining these classifications with Iowa's population estimates for 2005, 54.8% of Iowa residents live in metropolitan areas, 17.6% live in micropolitan areas, and 27.6% live in noncore areas. Therefore, approximately half of the population in Iowa lives in a more rural area and thus, deserves attention especially with regard to workforce issues.

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[58] "Very Frontier" is a county with 0 to 1.9 persons per square mile.

[59] New Freedom Commission on Mental Health. *Subcommittee of Rural Issues: Background Paper*. DHHS Pub. No. SMA-04-3890. Rockville, MD: 2004.

[60] U.S. Census Bureau, Metropolitan and Micropolitan Statistical Areas, available at http://www.census.gov/population/www/estimates/metroarea.html

[61] Listing of core based statistical areas by the Office of Management and Budget (December 2005)

A recent study concerning barriers to mental health access was conducted by Iowa's Critical Access Hospitals (CAHs). Forty-eight of sixty-seven (72%) respondents deemed mental health services to be a key issue facing rural communities. The study identified reimbursement issues and lack of insurance coverage as primary factors affecting access to mental health services. Recruitment and retention of mental health workers were also identified as important issues. Although 90 percent of survey respondents indicated they were not recruiting mental health practitioners, the reason was mainly because the facility did not have a mental health unit. The study identified that wait times for outpatient services were reported most commonly as 1-2 weeks (43%). Waits of one week or less were cited by 34% of respondents while those reporting 4-6 week waits were 5 percent. Two percent reported 8–12 week waits[62].

The Western Interstate Commission for Higher Education (WICHE) Mental Health Program[63] convened two separate meetings (one in Reno, Nevada and one in Mesa, Arizona) that focused on behavioral health workforce issues. At both meetings, stakeholders from the public behavioral health system and higher education discussed ways to improve recruitment, retention, and training efforts in behavioral health. The second meeting held in Mesa, Arizona in March 2005 ("Building Partnerships in Rural Mental Health Workforce Development Meeting"), focused the workforce discussion through a rural lens.[64] WICHE collaborated with the *Annapolis Coalition* to merge efforts and inform the national strategy on issues germane to rural behavioral health.

One of the most durable strategies for addressing rural workforce issues includes creating new educational delivery methods and service delivery models to support "grow your own" initiatives.

The list below includes a number of other strategies that might be considered in Iowa:

- Increase mental health literacy in rural communities via educational campaigns;
- Increase behavioral health career information and recruitment efforts in middle schools and high schools;
- Facilitate partnerships between higher education, public mental health system, and local community
- Recruit people living in rural areas into behavioral health careers and utiilize incentives (e.g., loan repayment) to increase likelihood that they will return to their community;
- Increase rural training opportunities;

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[62] Center for Health Workforce Planning, Bureau of Health Care Access, Iowa Department of Public Health 2006 report, *Iowa's Mental Health Workforce*.
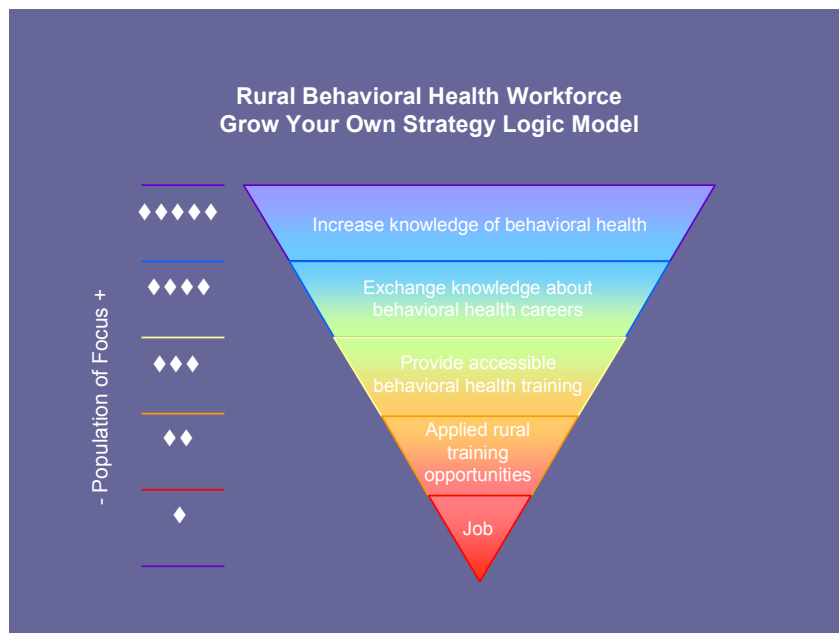[63] WICHE Mental Health Program www.wiche.edu/mentalhealth
[64] The "Mesa Report" can be obtained by contacting WICHE directly at www.wiche.edu

- Utilize distance technology to support and enhance education and training opportunities, access to providers in urban areas, and supervision of providers in isolated areas;
- Maximize natural community supports including identifying the best use of paraprofessionals and mid-level professionals to support workforce needs;
- Market behavioral and other health job opportunities to broader market (e.g., non traditional populations such as seniors, veterans);
- Develop a career ladder and articulated pathways to allow people choices along the behavioral health professional spectrum;
- Increase financial incentives for those who choose to practice in rural communities for an extended period of time; and
- Create applied educational and training programs that translate into a job in the workforce system.

The figure below is a graphic illustration of a logic model supporting the "grow your own" model. The model starts with impacting the highest numbers of people (i.e., educational efforts to increase knowledge of behaivoral health) and ends with individuals entering jobs in a specific workforce sector.

Rural Behavioral Health Workforce Grow Your Own Strategy Logic Model

- Population of Focus +

- Increase knowledge of behavioral health
- Exchange knowledge about behavioral health careers
- Provide accessible behavioral health training
- Applied rural training opportunities
- Job

Recommendations

1) One solution to the rural workforce problem in Iowa would be to expand the use of paraprofessionals to provide mental health services to rural populations. Alaska has implemented a certificate program for training paraprofessionals, whereby students meet for 1-3 weeks of intensive course work each semester to work toward an Associate of

Applied Sciences Human Services degree (see http://www.uaf.edu/rhs/). The certificate program could be implemented in online courses through Iowa's community college network. Each of Iowa's 15 community college districts offers distance learning options through online courses. These distance learning options may be ideal for rural individuals interested in becoming mental health service providers without having to travel large distances to attend courses.

2) Seek additional funding from the United States Department of Agriculture (USDA Rural Development Telecommunications Program: Distance Learning and Telemedicine Program) to support telehealth technology infrastructure and development. A rural-focused state plan should be developed to identify specific uses of potential grant funds. Visit the USDA Rural Development website for more information on funding opportunities and current funds allocated to Iowa programs: http://www.usda.gov/rus/telecom/dlt/dlt.htm

Also see the following reference for more information on delivering care at a distance: Telemental Health: Delivering Mental Health Care at a Distance - A Guide for Rural Communities - http://telehealth.hrsa.gov/pubs/mental/intro

3) Increase training to primary care providers. Primary care providers serve as the main entry points into the mental health system for rural citizens. Increasing primary care providers' knowledge of common mental health illnesses may increase early detection of mental health problems, as well as early referrals to mental health specialists, thereby limiting progression of the mental illness. Increasing primary care provider knowledge can be accomplished with targeted training on mental health issues and ways to identify them in the primary care setting. A great resource for such training is available through the MacArthur Initiative on Depression and Primary Care (http://www.depression-primarycare.org/).

At present, the majority of Iowa's counties are rural, and half of the population resides in these counties. Demand for services currently outstrips the capacity of the mental health workforce. The result is that those seeking services often have to wait longer and/or may have inconsistent treatment due to staff changes. As they wait, the severity of their problems often worsens, which can lead to mental health crises. Fortunately, there are numerous workforce development strategies that can address these issues. Several of them have been recommended here, however, due to unique rural cultures, workforce development strategies must be identified and addressed by stakeholders.

DEVELOPMENTAL DISABILITIES AND CO-OCCURING DISORDERS

Target populations and their workforce needs.

Current workforce issues in Iowa include many target populations who need direct care and personal assistance: people with mental illnesses, behavioral issues, and dementia; with developmental disabilities or brain injury; and individuals of all ages with physical disabilities. These issues cluster around particular themes, as reflected below.

a. Community and facility-based providers, as well as individuals hiring their own workers under self direction, report difficulties recruiting and retaining skilled and front line (direct care) workers

b. Factors impacting recruitment and retention of direct care workers include inadequate wages and benefits, demographic changes affecting the pool of prospective employees, and the characteristics of the work that make it unattractive, such as the high incidence of injury on the job and lack of professional career ladder.

c. Skilled worker shortages are particularly acute, especially outside traditional work hours.

d. Funding streams for HCBS community providers are generally inadequate to ensure staff are adequately trained.

e. Emerging demographic trends with serious workforce implications are the increased longevity of people with disabilities in general (both cognitive and physical), the aging of family caregivers (who provide 80% of long term care in the US) and the aging of the caregiver workforce.

Historic trends and stresses on the system.

In addition to the issues above, additional stresses on the system arise from a confluence of historical trends, and from interests which both compete and occasionally overlap. In summary form, the main themes are:

a. The movement to rebalance long term care.

  - Community provider capacity to provide HCBS is circumscribed by their ability to recruit and retain competent staff. Workforce issues are reportedly more acute in rural areas.
  - Iowa community providers cite both State Medicaid regulations (such as the 20% administrative cap, which limits the resources available for training) and county

reimbursement restrictions as barriers to having sufficient funds for paying competitive wages, offering benefits, and training/retaining staff.

- Community providers do not receive rate increases with the same frequency as institutional providers limiting the providers' ability to offer merit or cost of living increases to their employees. Even when they do receive those increases, their effect may be negated by the caps on reimbursement rates or on service units available to individuals.

- There is no centralized resource for specialized disability trainings in Iowa or funding assistance to assure trainings are accessible to all direct care workers. Many providers train staff in-house, and some collaborate in bringing in outside resources for such specialized topics as working with people with dementia or behavioral issues. Iowa Caregivers Association and others offer a few sessions on the needs of specific populations at their annual members' conferences.

- Anecdotes about inadequately trained HCBS provider staff, high turnover rates and inconsistency in the daily provider team have discouraged some families from pursuing community living options for loved ones.

- Some community providers point to need for funding to decrease the discrepancy in wages and benefits between State Resource Center and community-based employment.

b. Co-occurring Mental Retardation and Mental Health Issues

- Community mental health workers are not typically trained or experienced in working with people with mental retardation. This can result in misinterpretation of a client's behaviors. Individuals with mental retardation do not benefit from talk therapy if the therapist does not know how to ask the question at the level the person can understand.

- A treatment program for people with co-occurring MR/MH in Dane County Wisconsin reports 80% of the referrals to their program are individuals with mental retardation having escalated inappropriate behaviors due to a change in their environment or health status and an inability for them to tell their care giver.

- Community mental health workers need training on how to work with people with mental retardation. In addition, there is a need for appropriate referral mechanisms to professionals who can do behavioral analysis and to licensed professionals with experience in working with individuals with cognitive disabilities.

c. The move to organize and represent direct care professionals.

- The Iowa Caregivers Association, established in 1992, was the first statewide association representing the interests of direct care workers in the nation. It was originally oriented to CNAs, which shaped its agenda, but it now seeks to represent all categories of direct care workers.

- Its goals for its constituency include professional respect, improved wages and benefits, supportive work environments, access to training and career mobility, and leadership development.

- Recent priorities have included improved access to health benefits for workers, and establishment of training and certification requirements for various worker classifications, part of a broad strategy to professionalize workers.

d. Personal assistance services (PAS) as a disability rights issue.

- In the 1990's the disability rights movement began to focus on access to PAS as an alternative to institutionalization of people with physical disabilities. Most States now include PAS in their State Medicaid Plan.
- Iowa is one of 17 States without this personal care option, although personal assistance is available from community providers for people accessing supported community living services in the waiver.
- The Enhancing Community Options Workgroup in its 2006 draft report recommended that PAS be added to Iowa's Medicaid State Plan.

Building on current efforts.

There are numerous on-going initiatives by State and private entities to address various aspects of the workforce shortage. The initiatives spring from different perspectives on the issues, are uncoordinated, and offer only partial solutions.

a. Professionalization of direct care professionals.

- The Better Jobs, Better Care Coalition, established by a Robert Wood Johnson grant to the Iowa Caregivers Association (ICA), reviewed alternatives to improve access to health benefits. ICA is now allying itself with the movement in Iowa to promote coverage for the uninsured in general.
- The Iowa Department of Inspections and Appeals Registry for CNAs now has the capacity to develop a database on all direct care worker classifications. This information could be helpful to both agencies and consumers.
- The legislatively mandated Direct Care Worker Taskforce developed a preliminary set of recommendations for standardized training and certification requirements for worker classifications. The Taskforce's work received continuing support from legislative appropriations in the 2007 Session.

b. Facilitating access to personal assistance through self direction.

- IME is providing all waiver participants with the option of self directing "unskilled" services (those not requiring provider licenses) by developing and managing their own individualized budgets for those services. Because consumers using this Consumer Choices Option would be able to hire family, neighbors or anyone of their choosing as care providers, this was perceived as conflicting with the ICA and IDPH agenda to professionalize direct care workers.
- Specific concerns raised had to do with whether consumers faced higher health and safety risks due to poorly trained providers. IME points to national studies showing

higher consumer and worker satisfaction with self direction, and no increase in injuries. Extensive dialogue improved understanding by interested parties, and ICA and IDPH do not oppose self direction.

c. Impact of Iowa's long term care rebalancing on workforce issues.

- Rebalancing will accelerate with implementation of Money Follows the Person (MFP), which has a goal of transitioning 528 residents of ICFs/MR into more integrated settings.
- Families surveyed by Resource Center staff cited access to better trained staff at the Centers as a major incentive to keeping their loved ones in facility settings.
- Besides general concerns about recruitment and retention, community providers especially point to the need to secure and pay for adequate training for staff that may be ill-prepared to deal with consumers who have significant behavioral issues.
- Community providers anticipate particular challenges in recruiting supervisory staff, with the required qualifications and training.
- Self direction may help address agency workforce shortages in rural areas, by giving consumers more flexibility in hiring help.
- Both the ECOW and the MFP Partners Group of stakeholders recommended expanded use of telehealth to extend access to skilled services, for waiver participants generally and for community providers working with MFP participants who have behavioral issues.

d. Impact of mental health systems transformation on workforce issues.

- Expanding statewide access to 24/7 emergency mental health services will create new demands for recruitment and training of front line and supervisory staff that could affect the MR/DD system.
- Families and caregivers of people with a variety of disabilities including mental retardation and autism may begin to access community mental health centers for emergency assistance in addressing behavioral issues.
- The focus on evidence based practices in the treatment of diverse populations such as children with autism, people with chronic mental illness, and people with co-occurring disorders raises serious questions about how to organize and deploy resources for training. Adequately addressing current and emerging priorities will require a high level of collaboration among service providers, state agencies and funding sources, and entities potentially offering training.

Integration of approaches across the mental health, developmental, and co-occurring spectra is a persistent challenge, but Iowa needs to take the broadest and most inclusive approach to its workforce challenges if it is to serve its citizens with disabilities in the most effective manner.

PRIMARY HEALTH CARE AND BEHAVIORAL HEALTH INTEGRATION

Integrated Health Care

Integrated health care is a movement that is long past due.[65] Numerous leaders across the United States are calling for the integration of mental and physical health services. The President's new Freedom Commission on Mental Health states that, "Mental health is key to overall physical health" and that, "Collaborative care models should be widely implemented in primary health care settings."[66] The Surgeon General has called for the integration of mental health and primary care and convened a working meeting on the topic in 2001. A number of large health care providers, including Kaiser Permanente and the United States Air force, now provide integrated health care. In addition, many states are now launching integrated primary care projects. What is integrated health care and what is the impetus behind this growing movement? How can integrated care help address Iowa's mental health workforce needs?

What is Integrated Health Care?

Integrated health care generally refers to the provision of health care which addresses the biological, psychological, and social needs of individuals. It involves collaboration between physical health care and mental health (often referred to now as behavioral health) care providers. Mental health providers may be social workers, psychologists, psychiatrists, or mental health paraprofessionals. Integrated care can take many different forms. Providers may be located separately or may be "co-located," in other words, they may provide their services at the same location (e.g., a primary care office). The physician and mental health provider may communicate about patients very seldom or quite frequently. The highest level of integration occurs when providers are co-located and collaborate frequently, developing collaborative treatment plans for their patients. Integrated care, sometimes also referred to as collaborative care, is a young field and has not yet reached a consensus on its definition. It is practiced in a number of different settings, but can most often be found in primary care. This section will focus on integrated care in primary care settings because primary care has been the focus of much of the research and integrated care efforts that

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[65] Blount, A. (2003). Integrated primary care: Organizing the evidence. *Families, Systems, and Health*, 21, 121-133.

[66] New Freedom Commission on Mental Health, *Achieving the Promise*: *Transforming Mental Health Care in America. Final Report.* DHHS Pub. No. SMA-03-3832. Rockville, MD: 2003.

have occurred thus far. In addition, the primary care setting offers an innovative way to fulfill mental health care needs in the state.

Integrated Care: Improving Overall Healthcare and Addressing Healthcare Deficits

Many people come to their primary care physician for help with conditions such as depression and anxiety or complaints that represent underlying mental health issues. For the ten most common symptoms reported in primary care, including, insomnia, headache, dizziness, and fatigue, biological causes can be found only 25 percent of the time.[67] About half of the care for common mental health disorders, such as anxiety and depression, is provided by primary care physicians.[68] Yet most patients presenting with such mental health needs do not receive effective and appropriate mental health care.[69] Physicians are often overwhelmed by short visit times with patients who present with long lists of physical complaints. The average primary care visit lasts between 13-16 minutes during which time physicians are asked to address an average of six problems.[70] Physicians are often forced to choose between mental and physical health needs, rather than addressing both. In addition to reducing a person's quality of life and ability to function across multiple settings (e.g., work, social), mental illnesses, such as depression, are also linked to poorer physical health outcomes.[71] Integrated care improves overall healthcare by providing services where and when they are needed. It also provides assistance to patients who have significant behavior change needs. We are living in a time in the United States in which the primary causes of death have shifted from acute and infectious disease to chronic and modifiable behaviors such as smoking, lack of exercise, and overeating.[72] It is estimated that more than half of the patients seen in primary care settings could benefit from behavior change assistance.[73] Offering integrated primary care to patients guarantees the availability of

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[67] Kroenke, K., & Mangelsdorff, A. D. (1989). Common symptoms in ambulatory care: Incidence, evaluation, therapy, and outcome. *American Journal of Medicine*, 86, 262-266

[68] Kessler, R. C., Nelson, C. B., McGonagle, K. A., Edlund, M. J., Frank, R. G., & Leaf, P. J. (1996). The epidemiology of co-occurring addictive and mental disorders: Implications for prevention and service utilization. *American Journal of Orthopsychiatry, 66,* 17-31.

[69] Wang, P. S., Demler, O., & Kessler, R. C. (2002). Adequacy of treatment for serious mental illness in the United States. *American Journal of Public Health, 92,* 92-98

[70] Williams J. W., Ross K., Deitrich, A. J., Ciootti, M. C., Zyzansky S. J., & Cornell J. (1999). Primary care physicians' approach to depressive disorders: effects of physician specialty and practice structure. *Archive of Family Medicine*, 8 (1), 58-67

[71] Ford, D. E., Mead, L. A., Chang, P. P., Cooper-Patrick, L., Wang, N. Y., & Klag, M. J. (1998). Depression is a risk factor for coronary artery disease in men: The precursors study. *Archives of Internal Medicine, 158,* 1422-1426.
Frasure-Smith, N., Lesperance, F., Juneau, M., Talajic, M., & Bourassa, M. G. (1999). Gender, depression, and one-year prognosis after myocardial infarction. *Psychosomatic Medicine,* 61*,* 26-37.
Gupta, A., Pansari, K., & Shetty, H. (2002). Post-stroke depression. *International Journal of Clinical Practice, 56,* 531-537

[72] Gribble, J. N., & Preston, S. H. (Eds.). (1993). The epidemiological transition: Policy and planning implications for developing countries. Washington, DC: National Academic Press

[73] Blount, A. (2003). Integrated primary care: Organizing the evidence. *Families, Systems, and Health*, 21, 121-133

clinicians who practice effective behavioral treatments that can prevent both the worsening of physical illnesses and the need for more expensive medical care.

Having mental health practitioners in primary care offices is also a means of working to increase acceptability and accessibility of mental health care. One of the goals of the President's New Freedom Commission on Mental Health was to decrease stigma related to mental illness, a problematic barrier to treatment reference. Access to mental health care is a major deficit within our current health care system. Patients who would not normally see a mental health provider due to stigma, lack of awareness of a mental health problem, time constraints, or other reasons have easy access to mental health providers without having to contend with stigma or other issues related to being seen in an off-site mental health clinic. Placing mental health care side by side with physical health are also suggests the importance of mental health by serving as a reminder that mental health is an essential component of overall health. Opportunities for access to mental health care are increased by bringing the service to the people, rather than the people to the service. This is a significant step considering the fact that patient follow through with mental health referral in primary care tends to be poor.[74] Access to a mental health provider on site has been shown to increase the percentage of patients who will actually follow-up with needed mental health care after a referral from their primary care physician.[75] Patients treated in integrated care settings also have increased access in terms of opportunities for prevention, screening, and early detection of mental health problems before they become more serious. In addition, integrated care can address high cost, poor clinical outcome medical care by working with patients on such issues as treatment adherence. Integrated care has been shown to improve adherence to medical treatment as well as consumer and health care provider satisfaction.[76]

Models of Integrated Care

As mentioned above, integrated care occurs along a spectrum and therefore offers no singular correct model. The level of collaboration and the location of providers (i.e., separate locations or co-located providers) determine the level of integration. Several large health care providers have already implemented the integrated care model. It is being used in some primary care offices in a number of states and is part of family medicine physician training as well. Interventions in these settings may occur spontaneously or may be

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[74] Gonzalez, J., Williams J. W. Jr., Noel, P. H., & Lee, S. (2005). Adherence to mental health treatment in a primary care clinic. *Journal of the American Board of Family Practice*, 18, 87–96

[75] Apostoleris, N. H. (2000). Integrating psychological services into primary care in an underserved community: Examining the referral process for on-site mental health services. Presented at the Northeast Regional Conference for the Society of Teachers of Family Medicine, Philadelphia

[76] Blount, A. (2003). Integrated primary care: Organizing the evidence. *Families, Systems, and Health*, 21, 121-133

targeted to specific populations in need. For example, integrated care may be provided for a new mother who presents to her physician requesting help with post-partum depression. Alternatively, interventions may target specific populations in need, such as depressed individuals or diabetics. One excellent example of a targeted intervention and successful integrated care model can be seen in the IMPACT program.

An Example of Integrated Care

The IMPACT program, which stands for Improving Mood Promoting Access to Collaborative Treatment was designed to improve the treatment of depression in older adults. Unutzer and his colleagues, who studied the program, describe a treatment team consisting of primary care physicians, psychiatrists, and a care manager (psychologist or nurse) who provided personalized treatment plans based on patient preferences and who follow-up proactively with patients. In their study, published in the Journal of the American Medical Association[77] a group of depressed older adults were initially educated about depression and offered medication or a 6-8 session focused course of psychotherapy. Depression education and therapy were provided in the primary care office. Further treatment options were offered for people who did not respond to the first round of treatment. A second group of subjects was seen by their primary care physician and given primary care treatment as usual. The study looked for a 50 % or greater reduction in depression symptoms as compared to baseline and found that 45% of the IMPACT group experienced such a reduction compared with only 19% in the treatment as usual group. The IMPACT group also reported lower depression severity, greater satisfaction with care, and less functional impairment. Other studies have also shown the effectiveness of integrated care for depression and other common problems in primary care.[78]

Recommendations

The current workforce development effort in the state provides an opportunity to employ innovative and effective approaches like integrated care. The state should consider whether it would like to utilize integrated care as a means of increasing access to mental health services. If integrated care is pursued in Iowa, recruitment and retention, as well as training

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[77] Unutzer, J., Katon, W., Callahan, C. M., Williams, J. W., Hunkeler, E., & Harpole, L. (2002). Collaborative care management of late life depression in the primary care setting: A randomized controlled trial. Journal of the American Medical Association, 288, 2836-2845

[78] Simon, G. E., Ludman, E. J., Unutzer, J., Bauer, M. S., Operskalski, B., & Rutter, C. (2005). Randomized trial of a population-based care program for people with bipolar disorder. Psychological Medicine, 35, 13-24.

Katon, W. J., Roy-Byrne, P., Russo, J., & Cowley, D. (2002). Cost-effectiveness and cost offset of a collaborative care intervention for primary care patients with panic disorder. *Archives of General Psychiatry, 59,* 1098-1104.

Katon, W., Von Korff, M., Lin, E., Simon, G., Walker, E., & Unutzer, J. et al. (1999). Stepped collaborative care for primary care patients with persistent symptoms of depression: A randomized trial. *Archives of General Psychiatry, 56,* 1109-1115

and education efforts will be affected. To begin with, the state should focus on providing training and education in integrated care and should conduct small pilot tests to determine what will be an acceptable model for the state.

- Clinicians should receive training that prepares them to work in integrated care settings
  - Integrated care curriculum as well as clinical training opportunities should be offered physicians and mental health professionals while they are in school.
  - Continuing education programs could be offered to clinicians already in practice who are interested in working in integrated care settings. For example, the University of Massachusetts Medical School offers teleconference training for mental health providers which culminates in a certificate in primary care psychology.[79]

- Consider small, regional pilot tests in primary care clinics in the state. Once a successful model is developed in these pilot clinics, it can be expanded out to other primary care clinics.

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[79] For more information on this certificate program as well as national integrated care efforts visit http://www.integratedprimarycare.com/

WORKFORCE DEVELOPMENT FINANCING

In its development of a national action plan on workforce issues, The Annapolis Coalition addressed the issue of financing the behavioral health workforce.[80] The findings were complex and in some sense troubling, as the quote from the report at left reflects. There are structural gaps in the way services are sought and delivered, which results in an especially complex set of interactions among consumers, providers and purchasers of services. As Tompkins *et al*. explain it: "First, a large gap exists between the level of clinical need in the population and the funding available for services. The gap consists of two parts. A significant portion of the population needs but does not receive treatment, while other individuals receive some treatment, but not in adequate amounts or types of services. This leaves many provider organizations underfunded and overextended as they try to address the needs of individuals seeking care. Second, an accompanying suppression of wages and salaries for behavioral health workers hampers recruitment and retention and degrades the workforce in terms of the credentials, skills, and experience needed to meet extensive and diverse needs in the population." (p. 272)

> *For a variety of reasons, need for behavioral health services does not necessarily translate into demand that is actualized in the marketplace, nor does demand for specific services always coincide with what is*

As the funding of behavioral health and disability services has shifted in recent decades from virtually 100% state dollars to a variety of funding streams (most significantly Medicaid, in most states)[81], there have been increased pressures on some elements of the workforce. The availability of Medicaid services, for example, is contingent on a determination of "medical necessity" which then drives the need for specific credentials and skills mixes that did not correspond to the traditional mental health and disability workforce pools.

Tompkins *et al.* indicate some directions for resolving the issues of workforce financing. The first are directed at influencing the marketplace:

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[80] Tompkins, CP, Merrick, EL, Reif, S and Horgan CM. (2007). Financing issues in the behavioral health workforce. Chapter 21 of Hoge, M. A., Morris, J. A., Daniels, A. S., Stuart, G. W., Huey, L. Y., & Adams, N. (2007). *An action plan on behavioral health workforce development.* Cincinnati, OH: The Annapolis Coalition on the Behavioral Health. (Available on-line at www.annapoliscoalition.org or at http://www.samhsa.gov/matrix2/matrix_workforce.aspx

[81] Frank, RG, Glied, SA. *Better But Not Well: Mental Health Policy in the United States Since 1950.* Baltimore, MD: The Johns Hopkins University Press; 2006

- Provide more and better private behavioral health insurance coverage.
- Increase public funding for services.
- Reform provider payments and payment mechanisms.
- Invest in technology.

The next set of recommendations includes both market forces and direct interventions to influence both the quality and quantity of the workforce:

- Raise workers' income and benefits.
- Diversify the recognized labor pool.
- Subsidize education and training.
- Regulate staffing levels and qualifications.
- Offer conditional public funding.

These global recommendations, of necessity, contain multiple complex sub-issues. A complete analysis of all of the options available to Iowa would be beyond the scope of the current review, but as Iowa moves to create a workforce collaborative and a center for improved competencies in the workforce, these recommendations can provide a matrix for additional study. In addition, changes external to Iowa could have significant impacts. For example, changes in such foundational issues as coverage for mental and substance use conditions on parity with other medical conditions would have an immediate and significant impact on workforce financing.

GLOBAL RECOMMENDATIONS

There are specific recommendations embedded throughout the report. All of these will not be repeated here, as some are best understood nested in the context of the report narrative and are specific to target areas or populations. The authors have chosen six over-arching areas that offer Iowa opportunities for substantive change, and we have highlighted those.

ONE: INCREASE THE USE OF PEER SUPPORTS AND PEER OPERATED SERVICES.

There is probably no single action that Iowa could take that would have more impact than expanding peer services. As we have noted in the body of the report above, there is a robust and expanding body of evidence supporting the efficacy of peer supports and peer operated services. Dedicated funding that would provide on-going training and support for these services could ensure a steadily growing cadre of individuals committed to improved services and supports. The use of evidence-based training strategies and greatly enhanced supervision strategies would further improve quality.

TWO: ENHANCE CLINICAL COMPETENCE THROUGH STRENGTHENED INFRASTRUCTURE.

Sustainable change in the quality of the workforce, both current and future, requires dedicated resources (both intellectual and financial) that give Iowa a focus for improving the competence of its workers, in whatever sector. Creation of an on-going workforce collaborative, as well as a Center for Clinical Competence and Training Institute, as has already been proposed by Dr. Parks (see Appendix D) is precisely the sort of infrastructure development that will yield recurring benefits to Iowa citizens with mental and disability conditions.

THREE: SYSTEMATICALLY PREPARE THE SYSTEM TO DEVELOP, IMPLEMENT AND SUSTAIN EVIDENCE-BASED PRACTICES FOR IOWA.

As is detailed in this report above (See Pages 44-48), Iowa has already been through a series of phases of work on evidence-based practices, and has an ambitious agenda of rolling our new EBPs in the coming three years. Going to scale, i.e. statewide implementation, especially in a rural state such as Iowa will pose innumerable challenges. The rural nature of much of the state also poses special workforce issues, which may necessitate studied modifications of the science-based intervention; tracking these modifications will be an important activity for Iowa and for other rural states.

FOUR: PROVIDE INCENTIVES FOR RECRUITMENT AND RETENTION OF BEHAVIORAL AND DEVELOPMENTAL SPECIALISTS.

Again, the report entitled *Strengthening Iowa's Mental Health and Disability Workforce: Building and Sustaining Competencies* referenced above and found in Appendix D speaks to this issue: "Under this special initiative, Iowa will establish s pool of dollars to offer financial incentives (stipends, loan forgiveness, supplements) to individuals in the high-need categories who are willing to help meet the skills deficits, especially in our rural and frontier communities. We will select those strategies that have been demonstrated to provide results, and match them to candidates who seem most likely to contribute to our system over time. Consumers seeking services in programs for those with chronic and persistent mental illness will benefit from the recruitment, placement and retention of up to eight psychiatrists, doctoral level psychologists or nurse practitioners with mental health specialization. Once placed in programs service the chronically and persistently mentally ill, these practitioners will provide professional mental health services to Iowans that do not receive the services now."

FIVE: INCREASE OPPORTUNITIES FOR INTEGRATION OF BEHAVIORAL AND PRIMARY CARE.

The appalling data on premature mortality for people with mental health diagnoses, which reflect that adults with serious mental health conditions die 25 years younger than their age cohorts without diagnoses [82]and the frequency of co-occurring conditions with all disabilities, demands more attention to integrating all aspects of health and wellness for people being served by Iowa's Division of Mental Health and Disability Services and its partner throughout the state.   This will require that professions traditionally associated with the specialty service sectors (psychiatry, psychology, social work, intellectual and development disabilities, etc.) will need enhanced education and support to modify practice behavior to attend to general health status, while community health providers will require education and supports to become more sophisticated in their recognition of and responses to behavioral health and disability concerns among their patient populations.

SIX: SYSTEMATICALLY EVALUATE THE EFFECTIVENESS OF IOWA'S BEHAVIORAL AND DISABILITY WORKFORCE EFFORTS.

As Iowa embarks on this ambitious agenda for workforce change, it is vital that metrics be developed to benchmark progress and to provide information on what strategies were successful and which were less so or not all successful. Not only is this an often forgotten

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[82] Manderscheid, RW, Druss, B and Freeman, E. (2007) Data to manage the mortality crisis. Accessed on February 5, 2008 at http://www.bu.edu/cpr/resources/wellness-summit/papers-and-presentations.html

element in change strategies, it is ultimately self-defeating as change strategies are not modified and improved as they meet the inevitable detours of real world system change.

SUMMARY AND CONCLUSION

This report reflects the efforts that Iowa has already taken, some current strategies that are in play, and a future agenda of work that will require years of concentrated effort to achieve. In our meetings with opinion leaders representing a wide range of Iowa stakeholders, we consistently found a high level of awareness about—and concern about—workforce issues in the state. That awareness and concern can fuel the efforts that lie ahead to transform the state's workforce for individuals with mental and other disabilities.

Both the Annapolis Coalition and the Mental Health Program of the Western Interstate Commission for Higher Education salute Iowa for taking on this challenge, and reiterate our willingness to assist Iowa as it moves forward.

APPENDIX A

General Recommendations and Strategic Steps for Telehealth in Iowa
Note: These recommendations are a part of a larger report by the Child Health Specialty Clinics noted in the reference section.

A Plan to Move Telehealth Forward

In order to move the telehealth system forward in the state of Iowa, several strategic steps are necessary. First, there are a set of general recommendations for the state:

1) It would be useful to undertake a surveillance effort to determine the current use of telemedicine and the numbers and types of patients being seen in this way should be implemented and monitored over time to see where these efforts are working and being sustained. This will be challenging, since we could find no evidence that this is currently being tracked, but it is necessary to determine capacity for expansion into additional areas.

2) There could also be a surveillance effort to determine the capacity across the state for telecommunications infrastructure that could support telemedicine, i.e. availability of ICN sites, availability of adequate high-speed internet access or T-1 lines.

3) Continued monitoring of the distribution of medical providers across the state is critical. The areas in the state where there are shortages of medical specialties should be assisted in exploring ways in which telehealth systems might be used to address those needs.

4) State policy makers should be given information about the uses of telehealth and given opportunities to talk with providers and consumers who are using it. They should be encouraged to consider policies that provide incentives for physicians willing to learn and practice in this modality as a way of expanding services to children with special physical and behavioral healthcare needs in the rural areas of the state.

5) Medical schools should be encouraged and assisted in developing training and practice opportunities for students who have an interest in using telemedicine in their practices.

In addition to these general recommendations, several strategic steps are necessary in order to advance telehealth and, specifically, to create a statewide system of specialty services available to rural populations through telecommunications technology. We are recommending a regional pilot approach, which could then lead, region by region, to the development of a statewide system:

1. Using a variety of population data, including the data included in this report, regarding location of pediatricians and child psychiatrists relative to child population, we would suggest the identification of a group of counties where there is an obvious need, an identified region to use as a pilot universe for the development of a telehealth system. Need

would be based on the population and provider data, and on the distance from specialty providers. Geomapping of child population and physicians would be particularly helpful in this process.

2. Within that region information would be gathered in more specific ways, by interviews or focus groups with local providers to identify priority needs. This information should include data about the incidence of special health needs, with behavioral health being one of those. It would be important to get information from local schools and other human service providers, as well as the medical community.

3. Because most areas of the state have a Child Health Specialty Clinic, and because these clinics have some experience with telehealth and have relationships with local providers, CHSC would be the logical entity to provide technical assistance, training and support in enhancing current systems and adding new telehealth systems.

4. From the data gathered in the region, one could project whether there is a critical need for pediatric services and/or child psychiatry services and/or other specialties, and approximately how much of each.

5. An assessment could then be made of the technology capability in the region. It is worth noting that not every community has access to internet bandwidth adequate for this type of use. On the other hand, hospitals already have T-1 lines in place and may be willing to collaborate with other entities in the use of these.

6. There are then several possibilities for expanding telehealth locations in the region. The CHSC clinic may be able and willing to increase the number of telehealth sessions. There may be a pediatric or family practice office that is able and willing to create a telehealth "studio" where their patients and their office staff could participate in specialty consultations. This would enable the rural practitioners to participate directly in the consultations they request for their patients. There may be a hospital that already has the necessary equipment and would be willing to partner in providing telehealth consultations for the community.

7. Obviously, the other necessary step is the recruitment and hiring of the required specialty providers who now reside and practice in urban settings and in tertiary facilities. They would have to be encouraged to practice in this new way and would need opportunities for training and practice, as well as time to build these new relationships across the state. Hopefully, one part of their telehealth practice would be providing education to the local practitioners who are caring for these patients with special health care needs, through modeling and through professional development, which will ultimately build the capacity of the local providers to deal with these issues.

APPENDIX B

Sommers, D., Campbell, J., and Rittenhouse, T. (1999).

Annotated Bibliography on Consumer-Operated Services

Missouri Institute Of Mental Health Program in Consumer Studies and Training: St. Louis, MO.

This annotated bibliography is based on a review of 59 articles about mental health consumer/survivor self-help groups and organized consumer-operated services. Both published and unpublished manuscripts, reports, and papers are included. This literature overwhelmingly supports the value of consumer/survivor involvement at all levels of the mental health delivery system, whether the consumers/survivors are working as peer-specialists in mental health centers, developing and participating in research, administering consumer-run services at independent or alternative programs, or delivering case management services within a team of professionals. Programs fall into four basic models of peer-support: drop-in centers, educational programs, peer-support groups, and peers as staff within a traditional mental health system. Consumer/survivor peer support services and programs grew out of both the patients' rights movement, a civil rights movement against involuntary commitment and forced treatment, and the general self-help movement in the United States. Consumer-operated services and peer-support promote the empowerment and self-determination of consumers/survivors, and continue to grow and develop in the United States and throughout the world.

Main points from material annotated in this bibliography include:

1. Support given by consumers/survivors tends to be more mutual and less hierarchical than support given by mental health professionals.
2. Empowerment of mental health consumers/survivors is critical in the consumer/survivor movement and works on a social level to eliminate stigma and discrimination, and on an individual level to support recovery.
3. Peer-led self-help groups have positive value as an adjunct to psychiatric care.
4. Self-help groups help to meet the increasing demands for mental health services.
5. Self-help groups need to maintain some autonomy from the mental health system.
6. Whether a consumer/survivor continues to attend a self-help group may be most influenced by the fit between the member and the group.
7. Online services are one effective way to access self-help.
8. Self-help groups are a growing social movement because they are responding to otherwise unmet needs of consumers/survivors.
9. Peer support services go beyond personal mental health issues to address poverty, racial tension, class issues, sexism, homophobia, and other forms of discrimination.
1. Self-help groups need to become more sensitive to the needs of culturally diverse populations, such as Latinos, African-Americans, and Gays/Lesbians.

2. Outreach to the African-American population in the area of self-help is important because African-Americans use these services at a disproportionately low level.
3. With the exception of people with substance abuse problems, women are more likely than men to seek self-help support.
4. Self-help and other consumer/survivor-driven services are cost-effective, but consumers/survivors need to be fairly compensated for the work they do. The literature advocates for equal pay and benefits for consumers/survivors.
5. The literature advocates for collaboration between consumers/survivors and professionals in the delivery of clinical and social support programs.
6. Consumers/survivors have much to contribute in terms of empathy, street smarts, encouragement of peers, role modeling, fighting stigma, and educating mental health professionals and researchers.
7. Because of their street smarts, systems knowledge, flexibility and patience, consumers/survivors are in a unique position to serve individuals who are both homeless and have a mental disability.
8. How to set boundaries between consumer/survivor case managers and their clients needs further exploration.
9. Consumer/survivor case management teams provide more effective case management than mental health professional teams without consumers/survivors as members.
10. There needs to be more evaluative research of consumer-run programs.
11. In order to understand how peer-support services work and for whom, alternative research methods--such as ecological, participatory, and narrative research--are needed, as are quantitative research designs and methods of assessment.
12. Consumers/survivors need to be involved in all phases of research on consumer-operated services, including the management, development, implementation, and interpretation of research projects.

Armstrong, M. L., Korba, A. M., and Emard R. (1995). Of mutual benefit: The reciprocal relationship between consumer volunteers and the clients they serve. Psychiatric Rehabilitation Journal, 19 (2), 45-49.

The Community Progress Service (CPS) was developed in 1986 by the Canadian Mental Health Association (CMHA) to increase the quality of life of individuals with psychiatric disabilities living in board and care homes. This report describes the (CPS) consumer volunteer program and presents the results of an evaluation of the program. The program was developed to integrate consumers in service delivery and provide some components of case management to individuals on the case management waiting list. CPS matched individuals with psychiatric disabilities (clients) one-to-one with other individuals with psychiatric disabilities who were further along in their recovery (volunteers). Although volunteers were not paid, they were given a monthly allowance to use as they saw fit. The program was coordinated by a person with a psychiatric disability.

Volunteers and clients were interviewed by a volunteer in another program. Anonymity was guaranteed. Sixteen active members were interviewed. Volunteers found that regularly discussing things in the Peer Support Network group was the most valuable part of the program. Few commonalities existed when volunteers were asked about the most difficult aspect of their job. However, all volunteers agreed that the most rewarding experience was seeing their partner enjoying the contact. Eleven of 12 volunteers indicated that they would

continue to participate despite the lack of payment, even though the lack of payment was a negative aspect of the work. Volunteers and clients rated the types of interaction they had with each other. No significant differences were found between volunteers and clients. Both groups rated providing support and encouragement and talking about problems, feelings, and concerns as most important. Most did not want to spend time talking about how to cope with their disability or specific aspects of it. An acceptance of each other seemed to exist because volunteers and clients shared a disability. Likewise, more empathy seemed to grow out of this volunteer and client commonality. Volunteers and clients seemed to benefit equally in terms of quality of life, personal development, activity levels, and sense of identity. Because of these benefits, the program was viewed as effective.

Budd, S. (1987). Support groups. In Budd, S., Harp, H. T., and Zinman, S. (eds). Reaching across: Mental health clients helping each other, Riverside, CA: California Network of Mental Health Clients.

Budd explains how support given by professionals is different from support given by peers. The latter is voluntary and not based on a hierarchy. Peers learn independence and develop our own power. The goal of support is not therapy but rather shared knowledge, caring, and encouragement. Budd warns against treating peers in the ways a therapist might, and outlines 10 things a support group can do. They include outreach, helping with income benefits, providing crisis response, providing psychosocial rehabilitation, providing supportive services of indefinite duration, providing adequate medical and mental health care, providing back-up support to family, friends, and community members, involving concerned community members, protecting client rights, and providing case management services.

Also discussed are things a support group cannot do. For example, giving support to family members directly is difficult because they do not necessarily trust our judgment. Our best mode of supporting families is to support the peers. Budd briefly discusses group rules, encouraging groups to keep them few and simple. Confidentiality is discussed at length and a foundation of dos and don'ts is offered for mutual support groups. Last but not least, Budd provides a lengthy list of pitfalls to avoid in the areas of leadership-membership and support, and three helpful questions to ask ourselves when giving support.

Budd, S., Harp, H. T., and Zinman, S. (1987). Reaching across: Mental health clients helping each other. Riverside, CA: California Network of Mental Health Clients.

This 238-page manual describes mental health consumer-controlled, self-help group issues. Twenty-four chapters are written by mental health consumers who have been involved in starting self-help groups. A glossary of much-used references and a 31-page guide to self-help groups are included.

Chapters 1-3 deal with definition and philosophy. Chapters 4-7 deal with setting up groups and providing a supportive environment. These sections are followed by four chapters discussing outreach to members, to the community, and to funding sources. Organizational structures and processes are covered by Chapters 12-17. Special activities, such as newsletters and conferences, are discussed in three more chapters. Finally, Chapters 21- 24 discuss challenges facing self-help groups, and offer possible solutions.

Chamberlin, J. (1988). <u>On our own: Patient-controlled alternatives to the mental health system.</u> England: MIND.

This book is written from the ex-patient's point of view and takes a look at psychiatry and alternatives to it. The book was published in the decade of the mental patients' liberation movement, when involuntary commitment affected all aspects of mental health care. Chamberlin discusses the overwhelming isolation and contempt most treatment imposed at the time. This book includes many personal anecdotes. Chamberlin makes a case for patient-controlled mental health services, which would be a real alternative to institutions that destroy people's lives.

The book includes nine chapters and an appendix listing United Kingdom groups run by patients and ex-patients. Chamberlin's ex-patient's point of view is clear in the titles of her chapters: "The Patient's View of the Mental Health System"; "The Making -- and Unmaking -- of a Mental Patient"; "Consciousness-Raising: Alternatives and False Alternatives"; "When People Go Crazy: Inside the Mental Patients' Association"; "Money -- and Other Practical Problems"; "Coercion or Co-operation?"; and finally "People, Not Patients," which seems to be the point of it all.

Chamberlin, J. (1997). A working definition of empowerment. <u>Psychiatric Rehabilitation Journal, 20,</u> 43-46.

According to Chamberlin, "empowerment" has become a popular term in mental health programs, yet it has lacked a clear definition. In a research project designed to measure empowerment in programs run by and for mental health service users, Chamberlin first attempted to develop a working definition of the term. Key elements of empowerment were identified, including access to information, ability to make choices, assertiveness, and self-esteem. Chamberlin's empowerment has both an individual and a group dimension. Details of the definition are provided, along with a discussion of the implications of empowerment for psychiatric rehabilitation programs.

A group of 12 leading U. S. consumer/survivor self-help practitioners formed the Advisory Board of the Center for Psychiatric Rehabilitation's research project. After much discussion, empowerment was defined as including at least 15 elements, such as having decision-making power and coming out of the closet. According to the Board, empowerment describes a process rather than an event. The article discusses each of these elements briefly. Chamberlin describes the research project, i.e. to define empowerment, as a starting point for developing a measurement instrument.

Chamberlin, J. (1995). Rehabilitating ourselves: The psychiatric survivor movement. <u>International Journal of Mental Health, 24,</u> 39-46.

When the author first became involved in the patients' rights movement, it was a small and unfunded civil rights movement. People joined because they wanted a voice in organizing to fight the system that had taken away their power. At the same time, the movement developed an innovative form of self-help/mutual-support services. Chamberlin briefly tells her story. She indicates that the key issue is forced treatment, which makes patients feel even more out of control. She writes about being the good patient while inside resisting. Until professionals are able to work in true partnership with us, patients will always be angry. Participants must become involved in a consultative, collaborative manner in research and

not be merely passive subjects of a research process controlled by others. Chamberlin includes examples of several client-run programs. She points out that patients create jobs and salaries for professionals while patients themselves live on tiny disability pensions which are often doled out by professionals, when professionals should instead join the movement and demand better benefits for patients. The author points out that it is particularly important that patients not settle for "rights" that are not rights at all. She gives an example of how the language in the United Nations declaration on patients rights was changed to be more restrictive. The National Institute of Mental Health (NIMH) has begun to involve ex-patients, survivors, and consumers in planning and evaluation meetings, despite criticism. Rehabilitation must not be viewed in a vacuum. Factors such as racism, sexism, classism, heterosexism, poverty, and oppression need to be factored in for professionals to see patients as not merely broken and needing to be fixed. Chamberlin states that rehabilitation must mean not only assisting with re-adaptation to society but recognizing the ways in which social practices prevent that re-adaptation. Stigma and discrimination must be honestly faced and fought.

Chamberlin, J., Rogers, E. S., and Ellison, M. L. (1996). Self-help programs: A description of their characteristics and their members. Psychiatric Rehabilitation Journal, 19, 33-42.

According to the authors, "user-run programs have proliferated in the past 10 years, yet there are few empirically-based studies about them. A survey of self-help programs was undertaken to increase understanding about the users ..., their demographics, and their perceptions of how such programs have affected the quality of their lives. Respondents were also asked about their satisfaction with user-run programs. The study was conducted using a Participatory Action Research paradigm (Whyte, 1991), using an advisory committee of persons who have used such programs, and with the intention of developing an evaluation methodology that could be replicated in future studies of user-run programs. Despite limitations in representativeness, these survey results are useful in understanding the perceptions of self-help members. Results of the survey and methodology are discussed."

The study was designed with the assistance of a consumer research advisory board, under the direction of the senior author. Three research planning meetings were held with the board to develop survey questions. The board decided to sample members of six self-help programs in various parts of the country. Because of financial limitations, only six out of 64 programs that expressed interest in the study were chosen. Programs were chosen based on geography, racial and ethnic makeup, and program type. They had to be consumer-run. Instruments for the study were also developed with help from the advisory board. Questions were developed using concepts from existing scales (e.g. quality of life and self-esteem); however, the board decided to avoid standardized psychological instruments, in favor of survey questions that were less potentially threatening to members. All ratings were based on self-report. A separate survey instrument was developed to obtain descriptive information about the programs themselves. The final instruments were pilot tested during the winter of 1991 at a local self-help program that was not scheduled to participate in the study. Data collection with the six selected programs began in March 1992 and concluded in August 1992.

Results indicated that site mission statements were developed solely by members, without collaboration with professionals or input from funding bodies. Keywords of these statements were content analyzed and found to promote empowerment and independence among members, to promote choice and self-determination, to provide peer support, and to offer

education, information, advocacy, and assistance to access services. Funding included the National Institute of Mental Health, the Center for Mental Health Services, their state Department of Mental Health, their Office of Vocational Rehabilitation, county or government boards, the U. S. Department of Housing and Urban Development, and charitable foundations. The number of full-time-equivalent staff ranged from a low of 1.5 to a high of 12.5. The most common job titles for consumers/survivors were advocates, peer support persons, resource coordinators, employment and education specialists, and residential support persons. The types of activities and services included assistance with legal problems, transportation, protection or advocacy for individual members, advocacy efforts on behalf of all persons with psychiatric disabilities, and assistance with housing. Programs were asked about the procedures that prospective members must follow to participate. Programs indicated that they had from 40 to 750 "active users" (a mean of 199 and a median of 65).

There were a greater percentage of male respondents than of female respondents. The average age of all respondents was 40.4. The sample consisted of 56.4% Caucasians, 36% African-Americans, and 7.6% other. Most respondents were single and more than half reported having children. The average age at first reported psychiatric contact was 23. Fifty percent of respondents reported currently taking psychiatric medication. The average total number of psychiatric hospitalizations was 4.8. The sample was fairly well educated, with the majority having at least a high school degree. Most respondents were not competitively employed. The median monthly income for respondents was $575. Most respondents lived in private homes or apartments. The authors compared and contrasted demographics of the self-help sample with data from a national sample of community support clients surveyed in 1984. Respondents were questioned about the number and types of mental health services they had used in the past year. From a list of 22 possible services, respondents had used an average of 7. The most frequently used services were counseling, medications, general support, transportation, emergency services, day activities, and psychiatric hospitals. Respondents were very involved in their user-run programs, spending an average of 15.3 hours per week there. More respondents were satisfied with their housing, social situation, and physical well-being than dissatisfied. However, most members were dissatisfied or very dissatisfied with their work and their finances. Respondents reported feeling more positive about themselves as a result of self-help involvement, having more respect for themselves, feeling more productive and capable, and being more able to recognize their strengths. Significant differences (p<0.05 level) were found in the impact self-help involvement had on respondents' social lives.

A 19-item questionnaire using a four-point Likert scale was administered to respondents to gather information about their satisfaction with their self-help program. Overall, programs received very positive ratings. There were no significant differences in satisfaction across the six sites. Over 90% of respondents indicated that they participated in at least one community activity and 40% indicated that they participated in five or more community activities. The author cautions about interpretation of the findings, because they represent only six of the 64 self-help programs that expressed a desire to participate, and because the researchers did not have the ability to systematically track response rates within each of the six programs.

Chesler, M. A. (1990). The "dangers" of self-help groups: Understanding and challenging professionals' views. In Powell, T. J. (ed), Working with self-help, (301-323). Silver Spring, MD: NASW Press.

This chapter looks at the dangers that professionals believe to be affiliated with self-help groups, points to vital issues in local self-help group-staff interactions and in professional-client interaction, and discusses how professionals and members of self-help groups can more effectively collaborate.

Discussed are structural distinctions of defining self-help groups' concerns, appropriate bases of knowledge, and authority for leading the groups. Also discussed are processes and different functions of self-help groups (i.e. education/discussion, counseling/therapy, and social advocacy). This chapter discusses potential "dangers" and sorts them into two different categories: dangers to members and dangers to professionals. Perhaps the most often mentioned danger is that discussions of deeply held feelings may escalate feelings and upset people in the group. Another danger is that medical misinformation will be spread and increase unrealistic hope. Some professionals argue that self-help groups are used as a "crutch." The author notes that dynamics of all groups, including self-help groups, may be seen as dangerous. Other professionals caution against members of self-help groups becoming too involved with each other's problems. The second major reported danger, i.e. the danger to the professional, concerns the development of an anti-professional or anti-intellectual stance among group members.

This author did research about the perceived dangers of self-help groups. Chesler gathered data on 63 professionals and 35 local groups that involved families and children with cancer. Some groups worked with professionals and some did not. Fifty-seven of the professionals interviewed reported that they had heard of dangers associated with self-help groups, but only 15 professionals reported that they had evidence of such dangers. Professionals worried that parents talking about feelings might experience greater pain and distress. Professionals were also concerned that self-help groups might threaten professionals' role and status. The author discusses the monopoly on service or practice by professionals and questions why any provider should be accorded special rights, pay, and privileges. Likewise, parents who become involved with self-help begin to hold the professional accountable for his/her actions and want to comparison shop. Professionals often defend themselves by defining the behavior of clients/patients and by defining the patient-professional relationship. Finally, the chapter advocates improving collaboration between professionals and lay leaders. Chesler notes that professionals' perceptions of dangers are greater than the actual evidence of dangers found in the literature. These perceptions must be demythologized. Professionals need to educate themselves and their peers, and to share actual experiences.

Consumer/ex-patients initiatives. (1998) Community Support Network News: A Network for Caring, 5, 1-16.

This newsletter offers a range of articles about consumer/ex-patient initiatives. One author (Parrish) gives a personal account of why she enjoys her work. (This article is briefed later in this annotated bibliography.) The National Alliance of Mental Patients and the National Mental Health Consumers' Association are described. What is happening now in Washington, D. C. is briefly summarized. The technical assistance section describes different demonstration projects. Sites included are in California, Colorado, Indiana, Maine, Missouri, New Hampshire, New York, Ohio, and Wisconsin. Examples of initiatives and services by ex-patients/consumers are given. These initiatives include: The National Mental Health Consumer Self-Help Clearinghouse; Outreach, Advocacy and Training Services for the Homeless Mentally Ill; and Colorado's Consumer Case Manager Program.

Foner describes the Leadership Education and Advocacy Development Mental Health Consumer Self-advocacy Training Project of the Pennsylvania Mental Health Consumer Association, funded by Pennsylvania Protection and Advocacy, Inc. Ebert describes the Alliance Peer Advocacy Service in Syracuse, New York. Ellis writes about mental health consumers in Mississippi. Blake provides an update on the Empowerment Sponsoring Committee, Inc., which is a coalition of mental health consumers, family members, advocates, and professionals working to create Massachusetts People Organized for Wellness, Empowerment, and Rights. The Consumer Speaks Conferences in California are described. Chamberlin writes about "An International Perspective -- User Involvement in British Mental Health Services." There are a resource guide to materials related to consumer/ex-patients perspectives, initiatives, and a research brief.

Corrigan, P. W. and Garman, A. N. (1997). Considerations for research on consumer empowerment and psychosocial interventions. Psychiatric Services, 48, 347-352.

In their abstract, Corrigan and Garman write, "Consumer empowerment is a political movement that, among many goals, seeks to diminish the stigma and discrimination experienced by people with severe and persistent psychiatric disorders. This article reviews research strategies that address the methodological problems of studying consumer empowerment. Key issues include defining the subject of investigation, describing consumer-developed treatments using discovery-oriented research strategies, and sorting out the diverse roles of consumers in contemporary psychosocial programs. Consumer empowerment introduces a political paradigm into the understanding of severe mental illness, a paradigm that can be difficult to integrate with the goals of empirical research."

Corrigan and Garman describe the difficulty of defining consumers. Inclusionary definitions are more consistent with the empowerment movement than exclusionary definitions are. The authors suggest using focus groups to list positive values and beliefs to work toward a definition. The authors compare ethnic groups and consumers but caution that the comparison may be limited. Corrigan and Garman also compare consumers and persons with physical illness such as AIDS. The latter analogies seem to reflect more of the stigma against individuals with serious and persistent mental illness. The authors also discuss whether the individual or the system needs to be studied. Most research has been oriented toward the individual, an orientation that often promotes stigma. The authors recommend studying the interaction between systems and the individual. The authors review several research projects about consumer-developed programs that show the effectiveness of consumers. The findings are questionable, however, because they rest on the null hypothesis. The authors suggest directly comparing consumer-run programs to non-consumer-run programs, using discovery-oriented research. The article discusses the consumer's joint role as participant and provider and the difficulty of such a role. The authors emphasize the importance of consumer participatory action research to advance research that supports the basic beliefs of consumer empowerment.

Curtis, L. C. (1993). Consumers as colleagues: Partnership in the workforce. Center for Community Change through Housing and Support, 4-5.

Curtis synthesizes interviews with 10 persons intimately involved with the process of hiring consumers as mental health staff. The perspectives include those of consumer-run and non-consumer run agencies, employees with mental illness, and supervisors. The article discusses the definition of the "consumer" and of possible roles. Possible roles include

volunteer; on-the-job training; created positions; set-aside positions; and competitive positions. Agencies should be clear about reasons for hiring consumers and should explore their own attitudes about the capabilities of persons with mental illness. The article suggests that training programs be developed to help the consumer and non-consumer staff work cooperatively. The agency needs organizational commitment, affirmative action, clear credentials and clear job descriptions, ongoing training and support, and perspective.

Dixon, L., Krauss, N., and Lehman, A. (1994). Consumers as service providers: The promise and challenge. Community Mental Health Journal, 30, 615-625.

In their abstract the authors state, "The importance of consumers in planning, providing and evaluating mental health services has received increasing recognition. Consumer participation as staff members on professional multi-disciplinary teams describes one model of consumer involvement in providing services. This report gives the perspective of the professional leadership of such a team which employs two full-time "consumer advocates" (CAs). CAs have made significant and valuable contributions to the clinical work of the team by virtue of their street smarts, engagement skills, peer support, positive role modeling, fighting stigma, and education of co-workers. However, the CA/professional collaboration presented a number of challenging questions for ongoing discussion, including: 1)What is the role of the CAs? 2) What are the boundaries between CAs and patients and the implications of these boundaries for the potential effectiveness of CAs? 3) What supervision should the CA have and with whom? 4) What is the impact of the CAs individual experience with mental illness on their work? Examples are presented of both the clinical contribution of CAs and how the importance of addressing the above questions became evident in the work of the team. The authors found that CA's were extremely important team members; however, an ongoing dialogue between consumers and professionals is essential to operationalize this important collaboration."

Like the self-help movement for alcohol addiction anchored in Alcoholics Anonymous, the mental health self-help movement is built on the assumption that reliance on professionals is not essential to become well. Self-help groups are non-hierarchical and emphasize self-definition of needs, voluntary participation, and autonomy. There are several models within which consumers can participate in the delivery of mental health services. This report describes the experience of an experimental Assertive Community Treatment (ACT) Team, designed to provide services to homeless persons with mental illness, which employs two full-time CAs. The ACT Team was started as the clinical arm of a National Institute of Mental Health McKinney-funded research project designed to measure the effectiveness of an assertive community outreach team. Patient and family outcomes, as well as costs of the ACT intervention, are compared with outcomes of a control group who received standard services in Baltimore City. The ACT team's first patient began with the team in March 1991.

CAs played an important role in the engagement of patients. The knowledge CAs had about different characteristics of the missions, shelters, and soup kitchens, as well as other aspects of street life, was important in many ways. Street smarts were critical. The CAs could more easily than other staff put themselves in the shoes of the patient. The personal experience of the CAs with medication, mental illness, and homelessness sensitized staff and influenced how the team provided treatment. CAs became role models for the patients and spoke in language the patients could understand. The CAs reduced stigma by challenging biases and prejudices which professional staff were not acknowledging. More casually dressed CAs seemed to suggest a tolerance that could only be expressed in

actions, not explained by words. The CAs handled money for a number of patients for whom the agency was payee. This seemed to lessen the humiliation for patients. CAs took patients shopping, directly helped patients deal with the frustrations caused by their illnesses, and discussed patients' feelings and decisions regarding medication. Finally, CAs functioned as patient advocates.

In implementing this model, CAs could have perhaps used more duties and structure. Boundaries between CAs and patients and between CAs and staff were not clear enough. Supervision was a question the project wrestled with. The Medical Director provided patient-based supervision in the model. The CAs found it ironic that a credential for the job was specific experience with mental illness and homelessness. Greater turnover among the CAs than among other staff appeared in some cases to be illness-related. Several CAs had never had an equal, cooperative relationship with a provider and were uncomfortable at first. The inability to bill for the services provided by the CA was a problem.

Felton, C. J., Stastny, P., Shern, D. L, Blanch, A, Donahue, S. A., Knight, E., and Brown, C. (1995). Consumers as peer specialists on intensive case management teams: Impact on client outcomes. Psychiatric Services, 46, 1037-1044.

According to the authors, "the objective of this study was to examine whether employing mental health consumers as peer specialists in an intensive case management program can enhance outcomes for clients with serious mental illness. Methodologically speaking, this study was a quasi-experimental, longitudinal, nonequivalent control group design used to compare outcomes of clients assigned to three case management conditions: teams of case managers plus peer specialists, teams of case managers plus non-consumer assistants, and case managers only. Outcomes were measured at baseline and at three six-month intervals. Repeated-measures analysis of variance was used to assess between-group differences. The results included complete data for 104 clients. Compared with clients in the other two groups, clients served by teams with peer specialists demonstrated greater gains in several areas of quality of life and an overall reduction in the number of major life problems experienced. They also reported more frequent contact with their case managers and the largest gains of all three groups in the areas of self-image and outlook and social support. No differences in outcomes were found between clients served by teams with non-consumer assistants and those served by teams with non-consumer assistants and those served by case managers only. The authors concluded that integration of peer specialists into intensive case management programs appears to lead to enhanced quality of life for clients and more effective case management."

Clients in the peer specialist group grew more satisfied with their living situations, finances, and personal safety than clients in the other groups. In addition, the number of major life problems the peer specialist group experienced declined relative to the other groups, which suggests that observed changes in satisfaction reflected not just changes in clients' attitudes but also objective improvements in their life circumstances. Fewer clients in the peer group reported poverty as a life circumstance. In the area of client engagement in the program, the rates of contact with intensive case managers remained stable for those in the peer specialist condition while rates declined in the other two groups. Although there were no statistically significant gains in self-image and outlook and social support, peer specialist groups show the largest gains.

Fox, L. and Hilton, D. (1994). Response to "Consumers as service providers: The promise and challenge." Community Mental Health Journal, 30, 627-629.

> The authors indicate that several issues are raised when consumers of mental health services are employed to provide the same services. Role definition for the consumer on the treatment team is one critical issue. The consumer on the treatment team should be an equal when it comes to supervision, pay, benefits, and status. The consumer is able to better engage others in pursuit of mental health. This capacity for engagement also requires some innovative approaches to the concept of "professional distance." The issue of relapse needs to be addressed when employing someone who has or has had a mental illness. A plan needs to be in place so other team members are not too burdened or resentful. This calls for maximum flexibility and accommodation in job description, sharing, and scheduling. Moving in and out of treatment in the community in which the team operates raises issues of confidentiality and boundaries. Using special skills and special knowledge gained from personal recovery is explored as part of a treatment approach to help others recover.

Galanter, M. (1988). Zealous self-help groups as adjuncts to psychiatric treatment: A study of Recovery, Inc. American Journal of Psychiatry, 145, 1248-1253.

> Galanter states in the abstract, "In a controlled study of Recovery, Inc., a self-help program for people with psychiatric problems, the author found a decline in both symptoms and psychiatric treatment after subjects had joined the group. Scores for neurotic distress reported after joining were considerably lower than those reported for the period before joining. Scores for psychological well-being of longstanding Recovery members were no different from those of community control subjects, and fewer long-term members than recent members were being treated with psychotropic medication and psychotherapy. The author concludes that peer-led self-help groups have value as an adjunct to psychiatric treatment."

> Recovery, Inc. is a voluntary, nonprofit association for mutual aid among self-described "nervous and former mental patients." There are weekly two-hour meetings which follow a particular format developed by the founder, Dr. Low. This format includes readings or an audiotape by Dr. Low, followed by patient presentations and then open exchange among members. Peer group leaders are selected after they have been members for a long time and have received training. The participants were Recovery, Inc. members and group leaders throughout each of the 211 Recovery administrative areas in North America. The research instrument was a 216-item multiple-choice questionnaire that was completed anonymously. In addition to demographics and Recovery-related activities, categories included mental health, neurotic distress, social cohesiveness, ideological commitment to Recovery, and psychiatric treatment. Respondents were 201 leaders and 155 more recent members drawn from 39 states, Puerto Rico, and Canada.

> The results showed that 310 (87%) of the respondents were white, 239 (67%) were married, most were middle-aged, 256 (72%) were women, and 231 (65%) had some college education. Two hundred ten (59%) worked for pay an average of 35.1 hours per week. Only 21% were referred to Recovery via the traditional mental health system. The peer leaders' involvement in the group was greater than that of the members. Both leaders and members, however, had attended the same mean number of meetings and had themselves made the same mean number of calls to ask for mutual aid. More Recovery members reported a history of "nervous breakdown" than did the control participants; however, the Recovery

members' psychiatric status seemed to improve after joining, as reflected in their responses to items on the Neurotic Distress Scale. Forty-nine percent of leaders and 52% of more recent members had been hospitalized for psychiatric problems before joining Recovery. After joining, 8% of leaders and 7% of recent members were hospitalized. Over the course of their longer terms of membership, the leaders needed less of both professional psychotherapy and somatic treatments. Participants in this sample of Recovery members reported close ties within the group: 77% said that they "care...a lot" (4 or 5 on a 5-point scale) for the 19 participants they knew best. This closeness was also evident in their responses to items about their belief in the ideas behind Recovery. A case report is provided to illustrate the impact of Recovery membership and its relationship to psychiatric treatment.

Gartner, A. J. and Riessman, F. (1982) Self-help and mental health. Hospital and Community Psychiatry, 33, 631-635.

In their abstract, Gartner and Riessman indicate that "over the past decade self-help groups have become an important way of helping people cope with various life crises. Groups have organized to help individual members deal with a wide range of health-related and other problems. The authors define the meaning of self-help in such groups and describe the range of groups now available, including a number of mental-health-related groups. The part self-help groups play in providing social support, preventing illness and death, and reducing the need for hospitalization is discussed. The authors also examine the role of professionals in initiating and working with such groups. They point to self-help groups as one means of meeting the increasing demands placed on health and mental health service systems during the 1980s."

The authors define self-help groups and discuss their own definition. For example, they explain that self-help groups always involve face-to-face interactions and often group members enter the group feeling powerless. Numerous groups are listed and self-help groups are discussed as a form of prevention. Self-help groups have developed to replace the natural support networks that have been lost or have become disconnected as society has changed. The power of self-help groups stems from their combining a number of very important properties: the helper-therapy principle, group reinforcement, continuous intervention, an ideological perspective, and the implicit demand that members do something for themselves. The authors argue that service delivery systems in the 1980s will require a strong relationship between professionals and self-help groups. Independence from professional intervention has been part of the self-help rhetoric from the beginning of the movement. Concern has often been expressed about professionals taking control of the self-help groups. Nonetheless, professionals have been involved for a long time. However, professionals need training in how to perceive a need, establish a self-help group to fill the need, and then disengage. The mental health field is particularly affected by the possibilities of self-help as mental health services are being strained more and more to meet growing and diverse demands. Self-help becomes a way to expand human services quantitatively by reaching more people, and qualitatively by making people more independent and interdependent.

Gartner, A. and Riessman, F. (1993). Self-help and health reform. National Self-Help Clearinghouse, 1-8.

Because health care needs in the United States are rising tremendously, it is impossible for the professional care-giving system to provide all the services that are necessary. Thus, the

self-help/ mutual-aid strategy becomes especially meaningful, because it turns people with problems into sources of care. A self-help approach can play a strategic role in the three key dimensions of health care reform: cost, quality, and access. Research supporting self-help has found that patients discharged from a state psychiatric hospital who were randomly assigned to participate in self-help required only-half as much re-hospitalization 10 months after discharge, compared to non-participating ex-patients. Self-help groups cost less than traditional treatment. In a survey of mental health drop-in centers, the cost of social support services provided at peer-run centers was approximately $250 per person per year, compared to about $500 per person per year in similar professional provider-run centers. Primary care physicians' role will be directed at providing quality care while limiting costs. There will be an emphasis on prevention and development and on use of a wide network of care, including self-help/ mutual-aid.

Although relevant groups exist, they are often inaccessible to those who need them and appropriate referrals are often not made by the professional community. On a macro-level, a national council of self-help with representation from self-help groups, consumers, clearinghouses, researchers, and health-care-providing agencies could play a coordinating role in this self-help initiative. On the local level, the task force could require that the HMO or other overseeing organization provide the community with referrals to self-help groups and with information about existing groups. Here, regional self-help clearinghouses could provide such information and access to the health-care system. Self-help groups have a vital contribution to make in a continuous evaluation of the health-care system. Self-help groups need to know about any health-care changes that are made known to professionals. Knowledge about self-help needs to be synthesized and delivered to the entire health-care community so that providers understand and appreciate the importance of self-help.

Gutierrez, L., Ortega, R. M., and Suarez, Z. E. (1990). Self-help and the Latino community. In Powell, T. J. (ed), <u>Working with self-help,</u> (218-236). Silver Spring, MD: NASW Press.

This chapter discusses using self-help in the Latino community to increase members' strengths and abilities. It describes several ways the self-help model can be useful in the Latino community. Cultural values of Latinos and how these values are different from those of the mainstream in this society are discussed. How the self-help perspective fits with aspects of Latino culture is also outlined. Finally, suggestions are made for professionals who have an interest in organizing self-help groups in the Latino community.

This chapter indicates that qualities of interdependence, symmetry, generosity, loyalty, cooperation, affiliation, collectivism, and social harmony are representative of the Latino self. This viewpoint illustrates how self-help could be philosophically compatible with the Latino culture. Instead of emphasizing self-help, however, the authors suggest emphasizing mutual-aid. Although Latinos are written about as a whole, many subgroups exist in the Latino community. Two of the barriers to organizing self-help groups are language and transportation. Child care and household responsibilities may limit participation of women. Many immigrants hold down two jobs and do not have the time to participate in self-help groups. Suggestions are given for organizing Latinos into mainstream, as well as "Latino only" self-help groups. The authors discuss developing Latino chapters of mainstream groups. The National Alliance for the Mentally Ill is one example. The authors do not believe that mutual-aid groups can come about without the involvement of professionals or "linkpersons." Once Latino leaders come forward, however, the authors recommend that the "linkpersons" step away. The chapter also discusses groups that are culturally relevant to

Latinos. Finally, self-help groups must be able to address a broad range of problems and must not turn away any Latinos who need support.

Howie, T. H. (1987). Oppression within the group. In Budd, S., Harp, H. T., and Zinman, S. (eds), Reaching across: Mental health clients helping each other. (188-193). Riverside, CA: California Network of Mental Health Clients.

This chapter discusses ways self-help groups can become oppressive. Conformity, standards of behavior, and judgments can all oppress members, especially new ones. Not respecting cultural differences, such as ethnic origin, national origin, social class, where a person grew up, religion, and sexual and other lifestyle preferences can also become oppressive. Harp states that differences and conflict are natural in groups. It is the taking of sides that becomes oppressive.

Avoiding debates over personality, especially debates in which the interests of the group get lost, is important. Severe oppression occurs when there is gossip about members or when members "gang up" on another member. Harp indicates that scapegoating can destroy people. Perhaps the worst form of oppression within a group is forcing a member into doing something he/she does not want to do. Another extreme form of oppression is letting philosophy or ideology become dogma for the group. Harp cautions against members becoming jealous of a highly contributing member. This chapter ends with ways to prevent oppression within the group.

Kasinsky, J. (1987). Co-optation. In Budd, S., Harp, H. T., and Zinman, S. (eds), Reaching across: Mental health clients helping each other. Riverside, CA: California Network of Mental Health Clients.

This chapter begins by defining co-optation as "the absorption into the mental health system of a heretofore viable self-help or ex-patient-run alternative" or "the intentional destruction of a self-help group by the mental health system." Kasinsky outlines the danger signals: (1)changes in the group's funding; (2) changes in the amount of decision-making power and supervision the ex-patient members of the group have over the group; (3) changes in the leadership whereby members who are not ex-patients take leadership and paid positions in the group.

Kasinsky discusses the importance of finding different kinds of funding sources and avoiding mental health system funding, especially when it involves collecting data. Another warning is given about using the language the funding source requires for grants and annual reports. Kasinsky cautions against letting that language direct and limit the self-help group's ways of thinking. Other cautions are given to ensure ex-patients are in the majority and are in leadership roles or being hired in paid positions. Many groups avoid co-optation by establishing clout in the community and through joining political action committees. Finally, Kasinsky cautions that constant criticism, self-determination, self-criticism, and evaluation are essential to guard against co-optation.

Kaufmann, C. L., Ward-Colasante, C., and Farmer, J. (1993). Development and evaluation of drop-in centers operated by mental health consumers. Hospital and Community Psychiatry, 44, (7), 675-678.

The Pennsylvania Office of Mental Health funded the development of nine consumer-operated drop-in centers, part of a statewide initiative begun in 1989 to promote consumer

involvement. This article describes some of the programs and services developed by the centers and presents results of a survey of consumers' use of and satisfaction with services. During the six-month survey period, a total of 478 consumers used services and the average daily attendance at each center was 28. Most centers had one paid position supplemented by heavy use of volunteers. Most projects had collaborative relationships with a few providers who maintained a low profile in daily operations. Although consumers were highly satisfied with the drop-in centers, respondents also wanted improvements in the number of paid staff, hours of operation, management, and transportation.

The $250,000 from state legislatures used the Involved Consumer Action Network (I CAN in Pennsylvania), which is a consumer-operated organizing agency, working closely with the Office of Mental Health (OMH). The article gives statistics on the number of inquiries and submissions regarding the project. Out of the 13 projects originally selected for funding in 1989, nine were successful in establishing centers within the first year. OMH established a process to gather information on the projects' use of funds and to evaluate consumers' satisfaction and use of services. Six core areas were examined: staffing, facilities and supplies, vocational programming, consumers' relationships with professionals, consumers' use of project services, and consumers' satisfaction with the centers. Some controversies arose in information-gathering, because the project directors wanted to avoid bureaucratic "red tape."

Each of the nine drop-in centers had a minimum of one paid staff member. All nine projects received technical assistance from providers who served as allies and consultants. Achieving balance between professional control and consumer control was a struggle. Four of the nine centers reported management problems due to competition for paid positions. The nine drop-in centers set their own hours. The space each of the centers used is described and location and access to public transportation are briefly discussed. The article provides a table giving the estimated attendance at nine consumer-run drop-in centers during a six-month period, by location of the center. Consumers' satisfaction with services was assessed during interviews and focus groups. Many consumers stated that they liked the centers' relaxed atmosphere and social activities. All consumers wanted to obtain money to expand social activities.

Finally, the article identifies characteristics of a successful center:

- Leadership and organizational skills
- Core group of consumer volunteers
- Interdependent relationships with providers
- Financial resources and accountability
- Planned social activities
- Ongoing recruitment of new members

Kennedy, M., Humphreys, K., and Borkman, T. (1994). The naturalistic paradigm as an approach to research with mutual-help groups. In Powell, T. J. (ed), Understanding the self-help organization: Frameworks and findings. (172-189). Thousand Oaks, CA: SAGE Publications.

Kennedy, Humphreys, and Borkman present an alternative way of studying mutual-help groups, with what they call the "naturalistic paradigm." The most popular belief structures now used for this research, which are the "positivist and post-positivist paradigms," are described and criticized. According to the authors, these two paradigms "hold that reality

exists out there and is subject to fixed natural laws and mechanisms." A summary of the criticism of positivist and post-positivist paradigms is given. Because people have seen so many problems with these beliefs, alternative paradigms for studying mutual-help groups have developed.

The naturalistic paradigm is based on believing that "objectivity" (or "absolute truth") is impossible. The social "reality" is being created by a person, who is usually in interaction with other people. According to Kennedy, et al., "The naturalistic paradigm assumes that all aspects of the phenomenon under study are interdependent and mutually interacting so that the determination of linear causality is impossible and inappropriate." The standards for judging naturalistic research include credibility, transferability, dependability, confirmability, fairness, and authenticity. The advantages of doing research about self-help groups with the naturalistic paradigm are described, along with examples of how the research can be used. Calls for naturalistic and qualitative research (which uses descriptions and people's own accounts of their lives, rather than using numbers) have gone out, but little of this research has been conducted.

Naturalistic research tries to work with self-help group members to determine how members benefit from the groups. The naturalistic approach asks for the researchers to be open about their subjectivity, meaning their own histories, prejudices, individual beliefs, hopes, and interests, etc. The authors stress how important it is to explore the range of experiences by group members. Kennedy, et al. caution that the information gained from a study like this must be understood in a context.

Outcomes like changes in world-view are usually not noted with traditional research . Members of self-help groups do not usually want to expose very personal changes to researchers who seem cold and distant. In contrast, the naturalistic approach to the study of self-help groups allows members to collaborate and to see the process of research as mutual, combining the different views and experiences of equals. The chapter concludes that the naturalistic approach will not solve all the problems related to studying self-help groups. The authors summarize some of the tough questions that need to be asked of the naturalistic approach and encourage researchers to consider both the approach and the questions.

Kessler, R. C., Mickelson, K. D., and Zhao, S. (1997). Patterns and correlates of self-help group membership in the United States. Social Policy, 27, 27-46.

In their abstract the authors state, "Data from a recently completed national survey are presented on patterns and correlates of self-help group participation in the United States. Over twenty-five million Americans are estimated to have participated in a self-help group at some time in their lives; over ten million, in the past 12 months. These estimates are conservative and might, in fact, be substantially lower than the actual numbers of participants due to the fact that groups organized or facilitated by professionals were excluded. Clearinghouse data show that professional facilitation is common in contemporary self-help groups."

Synthetic cohort analysis suggests that group membership has been rising over the past three decades, except in groups concerned with eating problems or with life transitions. Although self-help groups exist to address a wide range of life problems, more than one-third of participants -- accounting for more than 70% of self-help meeting attendance -- are

involved in groups for substance use problems. Large portions of people who use self-help groups for substance (50%) and emotional (76%) problems also see a professional for the same problems.

Self-help group participants are more likely than non-participants with the same problems to be young, female, white, and unmarried. Participants generally have lower incomes than non-participants, although the opposite is true in groups for eating disorders. People reporting less support and more conflict in their social networks are more likely to participate in self-help groups than people with more supportive networks. Generally, people with a lower sense of personal control and higher levels of neuroticism are more likely to participate in self-help groups. Extroversion, openness to experience, and commitment to personal growth are not significant predictors of self-help participation.

In the introduction, the authors indicate that the effects of self-help groups are part of a long-standing neglect of the self-help movement among human services professionals. The largest single sector in the American mental and addictive disorders treatment system is the self-help sector, according to a recent national survey. In this study 3,032 respondents were recruited and the ages were restricted to between 25 and 74. Participants were interviewed for 30 minutes over the telephone and also given a self-administered mail questionnaire. The mail questionnaire provided the following definition of self-help groups: groups organized and run by people who get together on the basis of a common experience or goal to help or support one another." More than one in six respondents participated in a self-help group at some time and 6.9% did so in the past year. Forty percent of the respondents who reported ever participating in a substance abuse group were still doing so during the past 12 months. Low median attendance in the past 12 months, in the range of between one and four meetings, is found among members of life transition groups, bereavement groups, disability groups, parent support groups, and groups for the families of people with physical illnesses.

The article discusses differences in lifetime participation. For example, the data suggest a steady increase in lifetime participation in self-help groups across the cohorts included in this survey. There was a substantial increase in lifetime participation in substance use groups after World War II and a steady increase also in more recent years. Many people who use self-help seek professional treatment also, particularly those who have psychiatric disabilities. Women are more than twice as likely as men to participate in self-help groups, with the exception of people with substance use issues. African-Americans overall are only half as likely as Caucasians to participate in self-help groups, but this difference is largely due to an extremely low rate of African-American participation in groups for people with eating problems. The study estimates that 25 million Americans have participated in self-help groups at some point, and this is considered a conservative estimate, since the survey excluded people under 25 and over 75 and did not include groups led by professionals. The study estimates that 10 million Americans participated in a self-help group in the past year.

Kopolow, L. E. (1981). Client participation in mental health service delivery. Community Mental Health Journal, 17, 46-53.

According to Kopolow, client participation is an inexpensive way of providing increased support and continuity of care, but it is underused. Self-help programs are not being used in the day-to-day operation of the community mental health centers (CMHC). Use of self-help programs in CMHC operations can surmount the difficulties of "limited motivation, capacities, organizational framework, and resistance by clients and professionals."

Kopolow discusses the ex-patient movement and the nearly unanimous opposition to forced treatment and the belief in patient input and direction of care. Kopolow describes seven potential benefits of more actively involving patients in their treatment. In 1981, data showing patient or ex-patient involvement in CMHCs were not even collected. In independent self-help programs, ex-patients provide support, friendship, and tolerance instead of psychotherapy, medication, and structure. The traditional mode of treatment often results in dependency and self-doubt. Kopolow states, "To offset this liability resulting from dependency, ex-patient groups have sprung up in all regions in the country."

Cooperation between ex-patient self-help groups and CMHCs can be beneficial. An example of this cooperation is given. In addition to independent self-help programs and collaborative programs, there is a third type of self-help program, advocacy. According to the author, this group has potentially the greatest impact on the mental health system. Kopolow explains that advocates must have their client's best interest at heart and must be loyal to the mission of helping clients obtain their rights and entitlements. CMHC staff may be reluctant to involve patients because of fear of losing staff power and ex-patients may be reluctant to collaborate because of fear of losing their independence and being co-opted. Nonetheless, Kopolow argues for greater collaboration.

Lieberman, M. A. and Snowden, L. R. (1994). Problems in assessing prevalence and membership characteristics of self-help group participants. In Powell, T. J. (ed), Understanding the self-help organization: Frameworks and findings, (32-49). Thousand Oaks, CA: SAGE Publications.

Lieberman and Snowden use secondary analysis (which studies information already collected by other people) to find how often and how widely self-help groups are attended. Two of the surveys covered large household probability samples, and a third survey looked at self-help groups in California. Accurately assessing self-help group participation based on the surveys is the focus of this chapter.

In the first study, 18,000 participants, who were not living in institutional settings, were analyzed. The survey asked a series of questions about resources used for psychiatric disorders and used for help with drugs and alcohol. The lifetime use of self-help groups was 3.6% for men and 2.2% for women. Other demographic statistics are also given. Caucasian groups show highest use, closely followed by Hispanics, and the African-American population reports the lowest use. Self-help group participation and psychopathology were analyzed. Over their lifetime, self-help group participants were five times more likely than nonparticipants to be classified as mentally ill using the DSM-III criteria. These differences disappear when current use and current DSM-III diagnosis are examined. Statistics are given on the relationships between types of mental illnesses and use of mental health services and self-help groups.

Another survey focuses on households, psychiatric treatment and symptoms, and use of self-help groups. During 1980, 5.6% of adults consulted mental health professionals, 2.9% participated in self-help groups, and 2.2% participated in some type of experiential education (or growth groups). The relationship between stress and the types of sources of help is analyzed.

The final study reviews self-help groups in California. Statistics are given on problems addressed by groups and whether the groups are led by a professional. The estimated

number of participants is discussed, as are selected characteristics of self-help groups. Those characteristics include leadership, new members, and services.

Luke, D. A., Roberts, L, and Rappaport, J. (1994). Individual, group context, and individual-group fit predictors of self-help group attendance. In Powell, T. J.(ed), Understanding the self-help organization: Frameworks and findings. (88-114). Thousand Oaks, CA: SAGE Publications.

According to the authors of this chapter, self-help is moving from simply an alternative treatment to a social movement. This chapter presents data on how participation of the member can be influenced by the "fit" between the member and the particular self-help group. Attendance and participation are connected and statistics that back up the connection are given.. The authors discuss different ways of defining the fit, such as self-help group/specific person, characteristics of the first meeting attended by the individual, and individual/other group members fit.

This study was part of a full scale assessment of GROW, Inc., a self-help group for people with serious mental illness or psychiatric hospitalizations. Within a 27 months, trained observers/participants collected data as they attended 527 meetings of 15 different GROW groups in central Illinois. Eight hundred, sixty-one different people, attending at least one GROW meeting, were observed. Participants ranged in age from 15 to 85 and tended to be single, Caucasian, and female and to have some education beyond high school.

An identification number was given to each participant to record attendance. Monthly attendance data were used to determine attendance duration for each member. A brief questionnaire about items such as education, marital status, work status, previous hospitalizations, and level of functioning was filled out by each member. The statistical method was discussed.

For the three models presented, the findings about participants most likely to drop out were:

1. For the individual characteristics model: younger, less educated, currently or previously married, and high functioning.
2. For the group context model: members who attend meetings that are more than 2:1 female.
3. For the individual-group dissimilarity model: different hospitalization history, different marital status.

The authors of the chapter emphasize that the concept of individual-group fit is critical to understanding how people enter a self-help setting and become participating members. This research is only the beginning and only exploratory. The chapter ended with four suggestions:

1. First meetings are important;
2. Be clear about for whom your group is organized;
3. Find out more about why people are or are not joining;
4. Recognize the need for change.

Lyons, J. S., Cook, J. A., Ruth, A. R., Karver, M., and Slagg, N. B. (1996). Service delivery using consumer staff in a mobile crisis assessment program. Community Mental Health Journal, 32, 33-40.

In their abstract, the authors state, "Interest has developed in the use of mental health consumers as staff members in community programs for persons with serious mental illness. The present study investigates consumer service delivery in a mobile assessment program designed to assist homeless people with severe psychiatric disorders. Consumer and non-consumer staff were generally comparable. Results suggest that consumer staff engaged in more street outreach and were less often dispatched for emergencies. There was a trend for consumer staff to be more likely to certify their clients for psychiatric hospitalization. In sum, consumer staff appear to provide a valuable contribution to this form of service delivery."

The introduction discusses the consumer movement, consumer staff, and mobile crisis assessment. A more detailed description of the methods of the study is given. The mobile crisis unit was funded in 1989 to serve a large Midwestern city. Nine consumer staff members were hired. Two consumers and two non-consumers qualified as examiners, who were able to hospitalize clients. For the first two years of the study, service data were collected on each open case. The results suggest that consumer staff can be a valuable addition to a mobile assessment program. There were few differences in the descriptions of clients served by consumer and non-consumer staff. There were several differences between the two groups in how they delivered services. Consumer staff engaged in more mobile outreach. Consumer staff teams were less likely to be dispatched in a emergency and tended to involuntarily hospitalize by certificate more often.

Madara, E. J. (1997). The mutual-aid self-help online revolution. Social Policy, 27, 20-26.

Online groups are growing because they are meeting otherwise unmet needs. Madara gives several eye-catching examples of how online services have been used. Online self-help networks go out of their way to get information to people. Online, any user can be of help to any other user. People who are immobilized by physical disabilities can participate. Madara gives examples of finding and developing communities online and discusses several advantages of online services, including no signs of social status, age, dress, weight, race, etc.

People dealing with rare disorders are especially helped by the internet. Madara points out how self-help groups are able to pool their members' experiences, knowledge, and practical information. Madara also discusses the down side of online networks, with the primary disadvantage being lack of universal access. Other drawbacks include inappropriate verbal behavior or harassment, junk email, intentional deception, and unethical research. Madara concludes that despite barriers and problems, online support groups and networks are growing and will no doubt continue to be use.

Madara, E. J. (1990). Maximizing the potential for community self-help through clearinghouse approaches. Prevention in Human Services, 7, 109-138.

Madara provides an overview of self-help groups and their relationships to prevention and mental health, suggesting that mental health centers would benefit from increased use and support of groups. He also suggests that the self-help clearinghouse approaches may be of special benefit. The development of an integrated and multi-disciplinary self-help clearinghouse approach is described. This approach will increase the awareness, use, and development of mutual-aid/ self-help groups in the community. The article contains examples of strategies and accomplishments in this area. Principles and concepts important

to professionals working with groups are discussed. Likewise, trends in the development of health-related groups and in computer conferencing are discussed.

In his overview, Madara cites the President's Commission on Mental Health (1978), which recommended increased linkage between mental health services and community support networks. Madara especially promotes self-help clearinghouses that help people find and form self-help groups. He suggests reasons increased mental health agency involvement with self-help groups can be useful: prevention, social networking, reducing incidence, etc.

Madara discusses professional involvement with self-help and the roles professionals have played in supporting groups. A major problem many professionals face is that they are not educated about self-help groups. The New Jersey Self-Help Clearinghouse was developed to educate professionals. Madara goes on to describe the development of self-help clearinghouses. He discusses goals, such as increasing the use of self-help groups by referring clients and clients' families to self-help groups and providing in-kind support to self-help groups by helping to arrange for flyers, telephone services, meeting space, secretarial services, mailings, and so forth.

The New Jersey Self-Help Clearinghouse and its history are described. The Center's first contact with self-help groups was an effort to simply identify their number and availability. Madara discusses how the Consultation and Education Department became known regionally for maintaining an extensive resource listing. Group development strategies emerged and a layout of that process is given. Clearinghouse operations and rationale are discussed. Outreach and education service are described, as are consultation and training service, the main thrust of the Clearinghouse program.

A section on empowerment versus enfeeblement is provided, with examples of how professionals can strengthen or weaken groups. Often the weakening of a group is done accidentally. Over the past few years, many professionals, institutions, and government agencies have become interested in self-help. Professionals have a responsibility to respect and support those empowerment efforts for the ultimate benefit of their patients and communities. Madara gives some perspectives on additional self-help trends. People with various individual illnesses and their families created health foundations, societies, and agencies dealing with their illnesses. As new health problems, such as AIDS and Alzheimer's, develop, it is often self-help groups that are the first to offer assistance. Madara concludes that self-help groups need to increase in number and size. One important way agencies and clearinghouses can tap the rich resource-building potential of self-help is to link people needing support with the self-help groups. Finally, group autonomy and ownership should be respected.

Madara, E. and White, B. J. (1997). On-line mutual support: The experience of a self-help clearinghouse. Information and Referral: The Journal of the Alliance of Information and Referral Systems, 19, 91-107.

This article discusses several forms of online mutual support/self-help, including benefits like overcoming barriers of time, distance, and disability -- and also describing some disadvantages. The authors conclude that this new tool has the power to help people become empowered and create their own communities in which they can share information which will help them overcome or cope with their obstacles.

The article discusses the beginning and growth of online self-help, and mutual support using commercial computer information services. The authors review CompuServe, America-On-Line, and Prodigy, pointing out that traditional self-help groups have been late to arrive online. Several dozen self-help groups are available to individuals, and now online services provide thousands of possibilities for those same individuals.

The authors also discuss bulletin board systems (BBSs). Hundreds are available across the country. A description of BBSs is given, along with how to use them. The article provides internet addresses to find a comprehensive searchable listing of BBSs and a comprehensive listing of freenets.

Mutual support through the internet is discussed. Self-help support networks usually take three primary forms:

1) Mailing lists or list serves

2) Usenet network, which provides access to thousands of News groups

3) World Wide Web

In addition, many people develop personal web sites where they share information and experiences. On the American Self-Help Clearinghouse, over 300,000 individuals per year are served and the internet is also working to assist in the development of new support networks.

The authors discuss characteristics of online support networks. Online services are available 24 hours per day, are less structured than traditional self-help groups, are an equalizer, are mostly anonymous, and can be used by many more people than self-help groups can.

Online networks provide social support, practical information, shared experiences, positive role models, helper therapy, empowerment, professional support, and advocacy. Online services are overcoming barriers of distance, time, and disability. Barriers to universal access, however, remain. Lack of universal access to telecommunications systems, resources, and networks represents a significant barrier. The authors advocate for universal access.

Maton, K. I. (1994). Moving beyond the individual level of analysis in mutual-help group research: An ecological paradigm. In Powell, T. J. (ed), <u>Understanding the self-help organization,</u> (136-153). Thousand Oaks, CA: SAGE Publications.

Maton makes a persuasive case for using the "ecological paradigm" for mutual-help research. A table, which represents a selected listing of variables important to self-help groups, is provided. Variables, such as focal problem, climate, structure, and well-being, are listed, and the levels of analysis include individual, group, and community. The types of vital self-help research hypotheses generated from an ecological paradigm are discussed. Variable domains and pathways through which well-being could be influenced via group characteristics are discussed. For example, groups with better developed ideology, climate, structure, and helping mechanisms are expected to have greater influence on the individual's adoption of similar characteristics. Maton indicates that more empirical research

is needed to find out which variations in group-helping ecology are linked to member well-being and how these patterns differ across dimensions of the group problem. Likewise, more research into member-group fit and member well-being is needed.

The influences of group, member, and community characteristics on group effectiveness and stability are discussed. Group, community, or member characteristics expected to be influenced are described. Maton predicts that the three areas of impact are lay and professional ideologies, referral networks, and community epidemiology.

Finding data that span many different categories and many levels of analysis is very important. Maton describes sampling and measures. He also emphasizes the importance of cross-domain (or cross-category)/within-level interactions, as well as cross-level interactions with the possible moderating effect of descriptive analysis. Finally, the prospect of combining ethnographic and quantitative research is discussed.

Menz, F. E. (1994). <u>Constituents make the difference: Improving the value of rehabilitation research.</u> Unpublished manuscript.

Menz states, "This paper discusses the participatory research model used by the Rehabilitation Research and Training Center at the University of Wisconsin-Stout. The goal of the presentation is to elaborate on the value added to the research process and relevance of research applications when research is rehabilitation need based and the research-to-applications process model is used. The sections of the paper cover the following: (a) What makes the Center work setting unusual for participatory approaches; (b) how the participatory model came about at the Center; (c) the two components of the model; (d) constituents and constituent involvement; (e) three examples from Center's use of the model; (f) guidance for making participatory models work; and (g) finally, a discussion of some of the promises and potential pitfalls of participatory models from the author's experience."

Studies are all planned around six stages of participatory research methodology: (1) identifying and prioritizing issues; (2) designing research plans; (3) collecting research data; (4) analysis and reporting; (5) synthesis and dissemination; and (6) transfer and application. Modifications of the research plan and the shaping of the potential products all come from the input and interactions between staff and the Constituency Advisory Committee members. The methodology helps to increase the likelihood that each study will yield additive value and will be completed in a timely manner. The research methodology is iterative and regenerative. This participatory methodology provides external reality checks so that there is higher potential for solving important problems in rehabilitation. The approach requires scientific rigor. The Center's program is a five-year network of closely related approaches for achieving solutions that may be used in different kinds of communities and by practitioners and consumers from different walks of life and different cultures, who have different disabilities. The more new knowledge is in contrast to commonly accepted practices, the less likely the knowledge is to be adopted through passive methodologies in the research-to-application process. This methodology recognizes that substantial change occurs over time and requires a variety of methodologies. The audiences of the program are clearly defined community-based staff and consumers. All published materials from the Center are made available in alternate formats appropriate to the needs of persons with disabilities and their families.

The article includes the following tables:

(1) a classification of research constituencies;

(2) examples of constituents' complementing each other in the research process;

(3) functions for constituents throughout the research process;

(4) a planning guide for involving constituents throughout research;

(5) a schema for evaluating constituency involvement.

The examples of research projects are community-based rehabilitation needs of Native American people with disabilities who live on a reservation; development of the vocational assessment protocol for planning and case management for persons with traumatic brain injuries; and development of a state rehabilitation plan for Ohio. In each section, constituencies, constituency functions, researcher functions, and special features that make the research work were identified. The author discusses assumptions about and definitions for research. He lists unresolved issues including research procedure issues, administrative and institutional issues, and ethical and evaluative issues.

Mowbray, C. T., Chamberlain, P., Jennings, M., and Reed, C. (1988). Consumer-run mental health services: Results from five demonstration projects. Community Mental Health Journal, 24, 151-156.

According to the authors, Project Ease-Out was initiated in a rural area to provide support to persons making a transition from the hospital to community living. A satisfaction survey showed success in the areas of interactions, responsivity, communication, and outcome. A major problem encountered was turnover among advocates. The Companions Program, also in a rural area, matched clients with volunteers to provide relationships in which clients could develop and practice social skills and engage in social activities. Although the goal of maintaining 12 matches was never achieved, progress was made in increasing eight matches in the first 12 months to 10 in the next six. There were few terminations and most matches continued beyond the required six months. The major problem was finding men to match with male clients. The goals of Project Stay were to provide a support network and help with life maintenance independence in the community. Contacts provided were 9,560 in response to 562 requests for assistance. Major categories were housing, transportation, legal, welfare, mental health, and other. Demographic and functioning level data on Project Stay clients were similar to data on inpatients. Daybreak Drop-In Center was developed in a suburban county to provide opportunities for consumers to enjoy activities and mutual support in an unstructured setting. A participant satisfaction assessment indicated favorable responses in a 10 to 3 ratio. Transportation was a difficulty at first, until the CMHC provided a van. Members were at first reluctant to locate their meeting place at the CMHC because of the possibility of stigma. Another problem at first was "non-mental health" attendees. The objectives of Winners Janitorial Services, a suburban project, were to establish a profit-making, consumer-owned and -operated, for-profit janitorial service, and to provide training and janitorial work for stockholding consumers. Winners employed a total of 11 consumers. Employment averaged 25 hours/week, at the federal minimum wage. The project received good local support but could not find enough customers to make a profit, so it joined with a sheltered workshop, enabling consumers to continue their employment/training experience.

The major problems with Winners were the supervisor's inability to market the service and the project developers' lack of business experience. Winners was never consumer-run. Since many of the consumers were on SSI, the amount of money they could earn without losing benefits was very small, thus interfering with full employment goals. The authors saw the consumer-run projects as successful, indicating the productivity and diversity of services possible among consumer groups. Costs of services were strikingly low due to minimum wage salaries paid to consumers and extensive use of volunteers. The projects filled important needs of the consumers and showed good cooperation with the community.

Mowbray, C. T. and Moxley, D. P. (1997). A framework for organizing consumer roles as providers of psychiatric rehabilitation. In Mowbray, C. T., Moxley, D., Jasper, C. A., and Howell, L. L. (eds), Consumers as providers in psychiatric rehabilitation, 35-44. Columbia, MD: International Association of Psychosocial Rehabilitation Services.

The authors present a framework and topology for describing and understanding the diverse ways in which consumers are involved in service provision in psychiatric rehabilitation. The purpose of this chapter is to acknowledge the diversity involved in consumer role innovation; to better understand the barriers and problems associated with consumer service provision, with experiences and outcomes that can be systematically analyzed; and to better understand and formulate solutions and policy responses using more systematic analysis. The authors discuss a framework for organizing consumer alternatives in the provision of services or supports in psychiatric rehabilitation. The two major components of this framework are the control of the consumer-based alternative and the purpose of the consumer-based alternative. This two-dimensional framework produces four types of consumer role innovations: consumer-run alternatives, consumers as employees, self-help alternatives, and consumer initiatives.

Mowbray, C. T., Moxley, D. P., Thrasher, S, Bybee, D., McCrohan, N., Harris, S., and Clover, G. (1996). Consumers as community support providers: Issues created by role innovation. Community Mental Health Journal, 32, 47-66.

Using data from Community Support Program-funded research demonstration projects designed to expand vocational services offered by case management teams serving people with serious mental illness, this article examines the issues created by employing consumers as peer support specialists. Roles and benefits of these positions are analyzed. Challenges experienced by specialists, the structure of the specialist position, the mental health system and the community, and personal issues are analyzed using data from the focus groups and the project's management information system. Role definitions, supports for role effectiveness, and the structuring of these types of positions are discussed.

The peer support specialists (PSSs) provided services to assigned individuals. Specialists might help consumers prepare resumes, set up bank accounts, acquire clothing for interviews or work, or learn the bus system. Roles and benefits of these positions were analyzed by collecting service activity logs (management information system data) and focus group data. Of the 263 persons served, 117 or 44% received some direct service from a PSS. Five to six PSSs worked per month, seven hours per week. The PSS staff worked with about 30 clients per month. The focus group sessions provided a discussion of the PSS role as well as an identification of challenges presented to PSSs personally, by their role, by the CMH system, and by the structure of the PSS position itself. The article provides suggestions for supports and structures to increase role effectiveness of the PSSs. The

mission and culture of community support systems need to be broadening opportunities for stakeholders other than professionals, particularly for consumers. Consistent mentoring and supervision of consumer employees is needed. Opportunities for education and advancement need to be available. The article concludes that consumers as community support workers can make a unique contribution to their peers within the community and on the job site. The authors point out that this role innovation can create considerable ambiguity, role conflict, role strain, and personal stress for the incumbents of these positions. However, the development and broadening of employment opportunities within community support systems is vital.

Mowbray, C. T. and Tan, C. (1992). Evaluation of an innovative consumer-run service model: The drop-in center. Innovations and Research, 1, 19-23.

In their abstract, Mowbray and Tan state, "This report describes the development and operation of demonstration projects designed to implement an innovative service model: the consumer-run drop-in center. Results are presented from a process evaluation, focusing on the extent to which the centers meet programmatic expectations, collecting retrospective satisfaction and impact assessments from participants, and examining differences in operations across the six centers studied. The evaluation found that the centers were meeting their mandates to provide acceptance, social support, and problem-solving assistance. The intended target population of persons with serious mental illness was being served. High levels of satisfaction were found, and participants reported feeling that they actually ran their centers. Retrospective accounts of positive effects of drop-in center participation were obtained. Consumer ratings varied across the centers, but satisfaction did not relate to attributes of a center's physical environment."

Some problems with relationships with the mental health treatment system in some locations, with funding levels, and with full participation of some subgroups of consumers were identified. Certain issues need attention in order to replicate this model, and to continue operations of the existing drop-in centers.

The article provides an introduction and background to the self-help movement, in addition to discussing the methodology of the study. The major data collection was through interviews with drop-in center participants via two site visits at six drop-in centers in Michigan. One hundred and twenty mental health consumers from the centers were interviewed. Questions in the study were: "What do consumer-run drop-in centers do?" "Are the centers really consumer-run?"; "What are the differences among the six centers?"; "Are drop-in centers helping their members?"; "What relates to member satisfaction with centers?"; and "Do all participants benefit equally from their centers?" The authors conclude that these centers were favorably evaluated by most consumers. This suggests that centers are worthy of funding and development by consumers working with advocates. These centers are truly consumer-run. Consumers not only need other consumers to start up and run this innovative model; they also need assistance (when it is asked for) from the professional mental health community. Funding needs to increase. Most participants, especially regular attendees, benefit. However, those consumers reluctant to speak out must be reached. The final recommendation of the article is that the centers be evaluated as a regular part of operations. Accountability and monitoring should play key roles in ensuring that goals of funding agencies, advocates, and recipients themselves are being met..

Neighbors, H., Elliot, K. A., and Gant, L. M. (1990). Self-help and Black Americans: A strategy for Empowerment. In Powell, T. J. (ed), Working with self-help. (189-217). Silver Spring, MD: NASW Press.

Neighbors explores several strategies for black people's progress, including the strategy of self-help. Since a racist society causes most of the problems facing blacks today, most black self-help organizations use efforts geared toward social and economic change. Traditional self-help for blacks has focused on improving personal competence to become more successful in the present system. There are many combinations of self- and system responsibility offered to explain and improve the status of black Americans. The chapter assumes that the "system blame" viewpoint leads to less self-determination than the civil rights and Black Power viewpoints do, and that too much blaming the system hurts traditional black self-help. The authors conclude that self-help can foster a more adaptive view of the black economic condition. People who help themselves and others are attempting to take control.

The chapter discusses both history and current efforts in self-help organizing. These efforts include self-help for economic, political, and social development; neighborhood-based groups for community development; church-based organizations for community development; black social institutions; self-help groups for coping with physical illness and death; groups to strengthen black families and youths; self-help organizations founded by black women; self-help organizations for black professionals; black chapters of mainstream self-help organizations; and self-help for black special-interest groups. This chapter approaches self-help from a social and structuralist viewpoint, i.e. the argument that points to the social cause of racism, discrimination, and injustice. On the other hand, the " self-blame/system blame" dichotomy runs through all discussions of self-help in the black community. Personal responsibility for advancing oneself as well as the group is important. A case against self-help is discussed briefly. The chapter concludes with a discussion of one of the most effective functions of black self-help, that of empowerment. Many black American are wondering where the 60s and 70s ideas of self-determination and self-sufficiency have gone. Governmental interventions like welfare and affirmative action may have dampened individual-level responsibility for solving black problems. Recommendations include development of theory for self-help programs within the black community; systematic, thorough, and longitudinal research geared toward etiology, maintenance, and success of self-help groups; and the extension of principles of self-help to all segments of black communities.

Noordsy, D. L., Schwab, B., Fox, L., and Drake, R. E. (1996). The role of self-help programs in the rehabilitation of persons with severe mental illness and substance use disorders. Community Mental Health Journal, 32, 71-81.

Substance abuse treatment programs in the United States frequently incorporate self-help approaches, but little is known about whether individuals with dual disorders use self-help groups. This article reviews several current studies on the role of self-help programs in treating substance use disorders among individuals with severe mental illness. These studies indicate that only a minority of individuals with dual disorders become closely linked to self-help. Psychiatric diagnosis and possibly social skills are linked to participation. Dually disordered consumers often experience 12-step philosophy and jargon as distancing and insulting. The authors suggest incorporating self-help approaches into the comprehensive community care of individuals with dual diagnosis.

Eighteen patients with alcoholism and schizophrenia were treated continuously between 1987 and 1991 in a community mental health center-based dual-disorder program that included intensive case management, substance abuse treatment groups, and linkage to self-help groups in the community. Linkage to self-help was promoted through development of motivation to attend meetings, education about the content and format of meetings, transportation, and a "double trouble" AA meeting specifically for people with dual disorders. The 11 people who attained full remission from alcohol disorders were compared with the 7 people who did not. Several clients in this study found self-help programs useful and were committed to participation. However, many people reacted negatively to the use of 12-step philosophy and jargon by clinicians.

Two other studies are reviewed. One is a survey of self-help use among a group of individuals with dual disorders who were treated by case management teams in the community, and the other is a follow-up of attendees of a residential dual-diagnosis program to evaluate outcomes, including self-help use. Both studies show that few individuals use self-help groups consistently over time, despite the programs' success in getting the majority of individuals to attend self-help meetings at some point. Diagnosis appears to be associated with intensity of self-help use in these study groups. Regular attendance at self-help programs seems to be more common among individuals with affective disorders than among those with schizophrenic disorders. Finally, better social ability appeared to be associated with use of self-help programs.

Parrish, J. (1988). The consumer movement: A personal perspective. Community Support Network News, 3, 1-3.

Parrish gives a personal account of what motivates her to do the work she does with the National Institute of Mental Health (NIMH). She explains that she is drawn to the individuals who have experienced the hardships of a severe mental disorder. The projects she has been involved in have been fulfilling because they affect so many people. She is also drawn to the concept of consumer empowerment.

Penney, D. (1997). Friend or foe: The impact of managed care on self-help. Social Policy, 48-53.

Penney advocates marketing self-help to managed care and explains managed care organizations (MCOs). Clear paragraphs define and describe, briefly, what MCOs are. Penney presents MCOs as first and foremost looking out for their financial well-being. Thus, self-help must be promoted as an economically good thing for MCOs. Penney talks about learning to speak the language; about bringing research to light that finds, for example, a relationship between self-help and improved survival rates or fewer mood disturbances for women with breast cancer.

Penney discusses health-care changes that may be beneficial to self-help groups. She lists a number of trends as they were discussed in Riessman and Carroll's Redefining Self-Help: Policy and Practice. Penney goes on to discuss two possible scenarios for the implementation of managed care for people receiving Medicaid. One is a best case scenario and the other is a worst case scenario. Supporters of self-help must take care that self-help is not used by MCOs to avoid their legal responsibilities to provide adequate health care. Other issues around the funding of self-help users and self-help providers need to be resolved. Much controversy exists in this area.

Policy in perspective. (May 1991). <u>Mental Health Policy Resource Center,</u> 1-8.

This edition is dedicated to self-help and includes research on self-help, examples of self-help, consumer/professional perspectives, and self-help resources. The edition begins with an article entitled "The Growing Mental Health Self-Help Movement." It discusses the numbers touched by self-help groups, what groups do, how they work, how they relate to "the System," the future of self-help, and policy implications. The article was adapted from materials on mental health self-help prepared for MHPRC by Susan Baird Kanaan. National Institute of Mental Health - funded studies of self-help are briefly summarized. The Center for Self-Help Research and Knowledge Dissemination, the Center for Psychiatric Rehabilitation, and the Center for Self-Help Research are all discussed. Examples of self-help groups and support centers include the Anxiety Disorders Association, National Association of Psychiatric Survivors, National Depressive/Manic Depressive Association, National Mental Health Consumers Association, On Our Own, Inc. of Baltimore, National Alliance for the Mentally Ill, Parents Involved Network, Oakland Independence Support Center, and St. Louis Self Help Center. An interview with Judi Chamberlin and Richard Lippincott explores consumer/professional perspectives, including questions like " What should policymakers be thinking about regarding self-help groups?" and "Are there ways in which professional/consumer collaboration can respond to these concerns?" A self-help core bibliography is provided. Jennifer Hartog reports on the Mental Health Liaison Group meeting. Other tidbits are the National Association of State Mental Health Program Directors recognizing the potential, unique contribution of mental health consumers; a brief discussion of diversity in Baltimore; online highlights; self-help: a Canadian perspective; and a brief discussion of GROW.

Rogers, S. (1996). National Clearinghouse serves mental health consumer movement. <u>Journal of Psychosocial Nursing, 34,</u> 22-25.

With the advent of managed care, the consumer/psychiatric survivor movement is in an ideal position to benefit from radical changes forthcoming in services to people with psychiatric disabilities. However, to maximize gains from the reorganization, the movement will have to organize itself. The National Clearinghouse organized Alternatives '96- - "Creating Healing Alternatives for Real Health Care Reform" --to explore and develop strategies for this process. The article describes the mission of the Clearinghouse and the survivor movement. The Community Support Programs (CSPs) are based on creating opportunities rather than fostering a lifetime of dependency and disability. CSPs try to tailor programs to people, rather than people to programs. The article discusses relevant computerized techniques, such as databases and the Internet. The Clearinghouse recently hosted the Second Annual National Mental Health Consumer/Survivor Public Policy Forum and invited consumer/survivor advocates to share effective strategies that they have used to gain access to the health care reform planning process. These forums try to get consumers involved, so that consumers and managed care executives can sit across the table from each other and engage in real dialogue about the issues that matter to them. Managed care is complex and for consumers to have an impact, they need to understand it. Likewise, executives need to understand consumer needs. The best chance for consumer-run services to play a larger role in these public mental health systems controlled by managed care will be to make new alliances that secure funding from managed behavioral health care organizations, while preserving the values and operational independence of consumer-run services. Demonstrating effectiveness in reducing dependence on psychiatric hospitals and other cost-intensive care will help.

Rappaport, J. (1994). Narrative studies, personal stories, and identity transformation in the mutual-help context. In Powell, T. J. (ed), <u>Understanding the self-help organization: Frameworks and findings</u> (115-135), Thousand Oaks, CA: SAGE Publications.

Rappaport defines the self-help community as just that-- a community-- rather than an alternative to professional psychiatric care. Rappaport discusses the pitfalls of viewing self-help as an alternative treatment. More specifically, Rappaport discusses the GROW study and illustrates some of the limits of the alternative service model in his own work with several colleagues. Rappaport emphasizes the value of narrative stories of individual people as opposed to "professional centrism" (i.e., viewing professional groups as more helpful than self-help groups).

Participants in the GROW meetings are described as feeling a part of a caring community. They have come from being hospitalized to having hope and being givers as well as receivers. Likewise, individuals in GROW seem empowered in their ability to make positive change. These stories are presented along with "professional patient" stories in which individuals see themselves as sick and dependent on medication for behavior, as people who receive services and who have little to offer anyone else.

Rappaport goes on to discuss self-help organizations as normative narrative communities that should not be compared to professional treatment. For example, when participation in a self-help group leads to substantive change in an individual's behavior or identity, it could easily be understood as a change in lifestyle rather than as a "treatment outcome." People joining a self-help group are making a decision, which is empowering, as opposed to receiving services. Rappaport describes narrative studies and community narratives and personal stories, as well as narrative structure, function, and change.

He lists six reasons why the narrative viewpoint is appealing:

1. Everyone knows what a personal story is. It gives people an opportunity to discuss their subjective experiences of both stability and change.
2. Personal stories are powerful, make sense, and are persuasive.
3. Personal stories are a way of communicating and defining oneself. They respond to change over time.
4. Narratives are always being created and revised and the storytelling process is active.
5. Direct cross-level comparisons between individuals and groups occur because processes mirror themselves in the narratives.
6. The narrative way of analyzing has been pursued in many fields, such as psychology, psychiatry, and applied social psychology.

Rapping, E. (1998). There's self-help and then there's self-help: Women and the recovery movement. <u>Perspective: A Mental Health Magazine,</u> 1-6.

Rapping briefly speaks of the many women entering the 12-step movement and of how the 12-step movement has been taken up by professionals, TV talk shows, writers, etc. History helps us to understand both the appeal to women and the appeal to society at large. The feminist consciousness-raising model is described. Rapping believes that model was a bridge, for many women in the 80s and 90s, to the 12-step model.

The section "From CR to 12-Steps" suggests why women in the 80s and 90s have been so invaded by addictive disorders. Cuts in child care, health care, welfare, education, and job training have forced women to work a "double day." As a result, we have seen more women seeking chemical and non-chemical "highs." The author describes "an unsettling sense of having bought into being a world view that has now, through mass media, become the dominant view of emotional suffering, its causes and its 'cures,' in which the very possibility of thinking or acting politically has disappeared." Rapping goes on to discuss the enfeeblement of calling oneself "sick" and argues that we should work instead to change the societal illnesses that have led to so many women becoming addicted.

Riessman, F., (1990). The new self-help backlash. Social Policy, 43-48.

Riessman describes critics of self-help groups, particularly of Alcoholics Anonymous. Critics of AA especially criticize the way members "admit powerlessness" over the disease. Different points made by critics are discussed and answered. For example, critics claim that members of self-help groups are becoming addicted to the groups themselves. Reissman's response is that self-helpers going to more meetings does not make them junkies. Rather, it makes them less isolated and more able to find a positive source for growth. Recent criticisms of self-help that deserve thoughtful attention are that identity-based self-help groups need also to go beyond the personal and to look at the other, less individual roots of the problem (such as addiction). Such roots include poverty, racial tension, sexism, etc. The article also discusses false empowerment, i.e., consumers being led to believe they can deal with their health problems through self-help alone.

Segal, S. P., Silverman, C., and Temkin, T. (1995). Characteristics and service use of long-term members of self-help agencies for mental health clients. Psychiatric Services, 46, 269-274.

This study examined the characteristics of long-term members of self-help agencies managed and staffed by mental health clients, exploring why clients sought help from the agencies, and how they differed from clients of community mental health agencies. Surveys and other measures were used to find information about the service use patterns of 310 long-term agency members, as well as about the members' resources, history of disability, functional status, psychological disability, health problems, and DSM-III-R diagnosis. Data from management information systems of the self-help and community mental health agencies were used to compare service populations. The self-help agencies served a mostly African-American population (64%), many of whom were homeless (46%). Eighty-seven percent had confirmed DSM-III-R diagnoses, and 50% had dual diagnoses with moderate to severe substance or alcohol dependence. They had sought help from the self-help agencies mainly for food or clothing, for a place to be, or because they were homeless. Finding counseling or help for substance or alcohol abuse was a less important reason for coming to the self-help agencies. A high proportion of the persons served by the self-help agencies in the study were homeless and had a dual diagnosis of mental disorder and substance abuse. The self-help agencies provided their clients with material resources while community mental health agencies provided therapy and medical care.

The self-help centers the authors studied were concerned with improving members' lives and helping them gain skills and resources to achieve stability, but the centers also place the responsibility to make the necessary changes on the members themselves. At the same time, the agencies believe that societal problems and injustices contribute to members' problems and that these injustices must be changed through people taking action together.

The survey was conducted in 1992 to 1993 in the San Francisco Bay Area. The mean client age was 37 and the median age was 38. Forty-six percent were actually homeless at present. In addition, 78% had been homeless at least once in the past five years, often for long periods. Eighty-seven percent of the respondents had been diagnosed with an illness in DSM-III-R. Half of the respondents had a dual diagnosis of mental illness and substance abuse. 98% had held jobs in the past, but only 24% did so at the time of the interview. Thirty-six percent received Supplemental Security Income or Social Security Disability Income and 36% received general assistance. 87% of respondents had experienced at least one of 16 major stressors in the past year. Stressors included being thrown out of or losing a place to stay, losing a job, spending time in jail or prison, grieving for the death of someone close, etc. Forty-six percent were referred by family or friends; one-fifth were referred by a mental health or social service agency; 20% heard about the agency by word of mouth on the street; and 10% happened to be walking by. Referrals included requests for food (26.3%), bus pass (28.5), place to shower (21.2%), clothing (36.9%), mailing address (42.3%), personal items (18.6%), temporary housing (34.3%), supported employment (22%), and services information (38.8%). Users of the two agencies were compared. The self-help agencies are able to attract and serve exactly the group of people they claim to serve and are intended to serve. The populations served by the self-help agencies and by the clinics operated by the community mental health agency overlap - 28% of these respondents were receiving counseling, and another 26% had done so in the past. This information suggests that self-help agencies, in combination with community mental health agencies, can serve a poor, mostly African-American, and often homeless population -- subgroups that are traditionally not well served by the mental health system.

Segal, S. P., Silverman, C., and Temkin, T. (1995). Measuring empowerment in client-run self-help agencies. Community Mental Health Journal, 31, 215-227.

In their abstract, Segal, Silverman, and Temkin state, "'Empowerment' connotes a process of gaining control over one's life and influencing the organizational and societal structures in which one lives. This study defines and validates three measures: the Personal Empowerment Scale, the Organizational Empowerment Scale, and the Extra-Organizational Empowerment Scale. Measurement efforts are based on observational work, baseline interviews with a sample of 310, and six month follow-ups with a sample of 241 in four client-run self-help agencies for persons with severe mental disabilities. All three study scales demonstrated strong internal consistency and stability. They were sensitive to user changes over time and have construct validity."

Segal, et al. discuss the meaning of empowerment in self-help agencies. Programs run by mental health consumers/survivors empower people because the contact with and reliance on peers encourages this grass-roots process. Essential characteristics of self-help agencies include client control of all program aspects, with independence from the mental health system; completely voluntary services; sharing of power within a structure that tries to avoid hierarchical relationships; and emphasis on addressing the economic, cultural, and social needs of members. Self-helpers see empowerment as related to self-efficacy, self-esteem, and the sense that positive personal change can come about through one's own efforts. Empowerment within an organizational or societal context, then, is seen as encouraging empowerment both in one's personal life and in the larger community.

Four self-help agencies in the San Francisco Bay Area were observed over a 12- month period. Baseline and six-month follow-up interviews were given. Three-hundred and ten

people completed the baseline interview with 248 (80%) completing the follow-up. The different scales used are given in the abstract. The people who were included showed stability and consistency over the 12 months in the following areas:

1) Direct Empowerment Measures

    a.   Personal empowerment
    b.   Organizational empowerment
          a.   Extra-organizational empowerment

2) Related Empowerment Concepts

    a.   Self esteem
    b.   Hope
    c.   Internal locus of control
    d.   Self efficacy

3) Functional outcomes

    a.   Quality of life
    b.   Independent social functioning

Self-efficacy, self-esteem, and internal locus of control have the highest convergent correlation. According to the study, organizational and extra-organizational empowerment measures depend more on involvement in the work role, while personal empowerment is more related to general independent social activity. Conclusions of the study are that empowerment is complex; the different areas of empowerment are related to different outcome domains, such as personal empowerment and extra-organizational empowerment; and self-efficacy is the bridge between the two main areas of empowerment.

Silverman, S. and Hamilton, H. Evaluation of an Alternative, Innovative Consumer-Run Model of Service Delivery: A Study of 'On Our Own, Charlottesville, Virginia': The Drop-In Center. Unpublished manuscript.

In their abstract, Silverman and Hamilton state, "Research on self-help for consumers of mental health services has traditionally focused on the operation of voluntary groups, such as AA, Mental Health Associations, etc., and has generally ignored service programs operated by consumers. This evaluation study focused on the only consumer-run program in the Commonwealth of Virginia, established three years ago in Charlottesville. The center serves a population of seriously mentally ill, homeless, and individuals with a history of substance abuse. The center is a private, non-profit, tax-exempt organization begun by consumers with a grant from the Virginia Department of Housing and Community Development, granted through the McKinney Act to serve the homeless. Now in its third year, though receiving financial support from state sources, the program remains true to its original ideals -- an all-consumer staffed service organization. Structured interviews of consumer-users of this program indicated that the program was meeting its funding intents of providing services for individuals either seriously mentally ill or homeless, by creating an environment that promotes social support and shared problem solving. The level of satisfaction with programs and environment was relatively high. Issues which have emerged

for future research include providing additional services for a dually-diagnosed population that may require more structure, establishing additional funding sources, and determining the long-term benefits of Drop-In Center participation."

The paper provides a brief literature review. The study asks whether the values of a consumer program are being met and whether the members of this Center are the targeted population of mental health consumers presently being served by the traditional, publicly funded system. Data were collected over six weeks by four graduate students who were not complete strangers to members of the Drop-In Center. It was made clear that interviewers had no personal stake in interviewee responses. Administration of each interview lasted 30 to 60 minutes. A brief demographic questionnaire was given, followed by the Degogatis' Symptom Inventory and Moos' COPES scale. The sample size was 24 members. The article gave demographics. The symptom scale was highest for the obsessive compulsive scale and the paranoia scale. The results of the COPES survey showed that on all three dimensions (relationship, personal development, and system maintenance and change), combined scores point to a very successful program. The strength of the program appeared to be on the dimension of relationship. The mean differences observed in the other two dimensions of the COPES, personal growth and system maintenance, show there is room for growth in program offerings. Increased training among consumer staff who provide peer support may be needed. Demographic data indicate that the people benefiting from the Center are mainly the target population: mental health consumers, the majority of whom have histories of hospitalization.

Snowden, L. R. and Lieberman, M. A. (1994). African-American participation in self-help groups. In Powell, T. J. (ed), Understanding the self-help organization: Frameworks and findings, (50-61). Thousand Oaks, CA: SAGE Publications.

This chapter reviews the literature regarding African-American participation in the self-help movement. There has been long-term involvement in civil and fraternal organizations, but African-Americans have had little perceived involvement in one-on-one participation in mental or physical self-help. Among surveys inquiring into self-help use, only the Epidemiology Catchment Area (ECA) obtained a significant number of African-American respondents. The reason for that significance appears to be the size of the ECA sample and the over-sampling of African-Americans. The authors studied the ECA statistics and compared African-Americans to Latinos/Latinas and Caucasians. Data from the California Self-Help Center were also examined.

The ECA data were collected at New Haven (Connecticut), Baltimore, St. Louis, North Carolina, and Los Angeles. The ECA study told what percentages of the catchment areas were African-American. All together 4,300 African-Americans were surveyed and 12,152 Caucasians were surveyed. The California study has an active file of 4,000 self-help groups. The file contains items such as characteristics of participants and other variables. Over a lifetime, approximately 3.6% Caucasians and approximately 1.1% African-Americans reported having used self-help groups. The chapter describes statistical methods finding that ethnicity and social class were independent factors connected to use of professional mental health, as well as self-help group services. African-Americans were compared to Caucasians and Latinos/Latinas to report self-help group usage. According to the results of the statistics, African-Americans use self-help groups at an especially low level. Likewise, African-Americans, when compared to Caucasians, with a DSM-III diagnosis were found to use self-

help groups at an especially low level. There was no evidence that African-Americans use religious leaders or alternative healers instead of using self-help groups.

In the California Self-Help Center report, the total membership of the groups was 373,000. The African-American membership was .4% and the African-American population of California was 7.4%. Recommendations are made for improving the ECA study, as well as the California Self-Help Center study. Education and community awareness of self-help groups are important, and groups should be geared more to the ethnic needs of the African-American community.

Solomon, P. (1994). Response to "Consumers as service providers: The promise and challenge." Community Mental Health Journal, 30, 631-634.

This article was written as a response to the article above by Dixon, Krauss, and Lehman. According to Solomon, the other article clearly shows the value of consumers as members of a multi-disciplinary team. However, Solomon points out, the consumer has not been accepted as a full fledged member of the team, but rather has been placed in a gray area between the service providers and the clients or patients. A clear role has been lacking, which leads to difficulties in implementing programs. Difficult issues include role responsibilities, boundary relationships, and supervision and support. According to Solomon, Dixon, Krauss, and Lehman describe staff as uncertain about what strengths consumers in general might have and as therefore permitting the job to be defined by the individual strengths of consumers filling it. The resulting problems cannot be explained as problems caused by filling the position with a consumer. Solomon questions why the consumer did not fill one of the case management positions, since significant contributions of the consumer advocate are characteristics of a good case manager. Case management is basically a service coordination job, which is ideal for consumers. She recommends substituting "life experience" for educational requirements. Solomon indicates that in the article she is responding to, the consumer advocate position was poorly defined and that the consumer advocate seemed to share many of the responsibilities of the case manager, which undoubtedly would result in some role conflict with the case managers.

According to the author, the ACT approach gives programs a chance to hire consumers as case managers, because it allows for services to be provided by other case managers in potential periods of illness and for the consumer case manager to hold a smaller caseload until she or he is properly trained. Both of these are reasonable accommodations under the Americans with Disabilities Act. An advantage of having consumers fill the position of case manager is that consumers could then bill for services. Mental health professionals must also recognize that not all mental health consumers will want to accept a job as a "professional consumer." The author cautions against putting another label on them and stresses the need to have more than one consumer on the team. She concludes that it is time to move beyond "professional consumerism" to real jobs for mental health consumers.

Solomon, P. and Draine, J. (1994). Family perceptions of consumers as case managers. Community Mental Health Journal, 30, 165-176.

In their abstract the authors state, "Family members of clients participating in a randomized trial of consumer delivered case management services were found to be satisfied with the services, without regard to whether or not their ill relative was served by a consumer case management team. While family members did not necessarily know that their ill relative's

case manager was a consumer, the attitude toward the capabilities of consumers serving as case managers was positive."

With deinstitutionalization, families have been expected to take more responsibility for their relatives with mental illness. Despite the added responsibility, families have not been given credit for all they are doing and at times have been blamed for their relative's disability. Families have often felt left out of the treatment process and dissatisfied with services. However, one area that has received a more positive review by families is case management services. As there has been increasing value placed on the views and contributions of families, so there has been increasing respect for what consumers have to offer. This study, which was conducted as part of a larger study, was designed to assess families' satisfaction with services received by their disabled relative from either a team of consumer case managers or a team of non-consumer case managers. Ninety-four clients identified a family member to be interviewed. A total of 55 family members were interviewed either by phone or in-person. Twenty-three of their relatives were served by the consumer team and 32 by the non-consumer team. The interviews were conducted at the 18-month point and included demographic information and satisfaction questions regarding services for both their disabled relatives and themselves. Family members were also asked questions concerning the qualifications of their relative's case manager and whether the family members would have any concerns if the case manager had experienced a mental illness him/herself. Initially, descriptive statistical studies were conducted. Subsequently t-tests and chi squares were used to determine whether there were differences in satisfaction for those whose relatives were served by the consumer and those whose relatives were served by the non-consumer team of case managers. Due to multiple tests of significance, a Bonferroni adjustment was used.

The sample of family members was mostly female (82%), with a mean age of 51 and an age range of 28 to 85. The majority were black (86%), with 11% white, 1 Hispanic, and 1 Native American. The average monthly income was $1137.63. Only 25% had less than a high school education. Forty-two per cent were currently working full time. In the client sample, 56% were male, most were black (86%), and most were never married (61%). The mean age was 40 with a range of 20 to 75. Almost three-quarters were on SSI/SSDI. Most (85%) were diagnosed with schizophrenia and almost all had had a prior hospitalization.

Family members with ill relatives who received case management from either a consumer or non-consumer team were highly satisfied with the service. The only area in which there was a difference in the views of families whose relatives received services from consumers was in the testing and monitoring of medication. When asked their opinion of the possibility of consumers serving as case managers, few family members gave negative responses. Families seemed more concerned with a possible change in case manager, regardless of which team served their relatives. There was no difference in symptomatology , or in clinical and quality of life outcomes of clients served by the consumer team. The authors caution that these results should not be used as support for employing consumer case managers as a cost-saving strategy. Consumers should be employed because they can do the job.

Solomon, P. and Draine, J. (1994). Satisfaction with mental health treatment in a randomized trial of consumer case management. The Journal of Nervous and Mental Disease, 182, 179-183.

In the abstract, Solomon and Draine state, "It was hypothesized that the clients assigned to a consumer team of case managers, because they share similar life experiences interacting

with the mental health system, would have greater satisfaction with mental health treatment than clients assigned to a team of non-consumer case managers. Ninety-one clients with serious and persistent mental illness randomly assigned to consumer and non-consumer case management teams were interviewed after one year of service. While clients served by a consumer team of case managers were less satisfied with mental health treatment, personal characteristics of individual case managers were more important in explaining differences in satisfaction with treatment than whether the client was served by the consumer or non-consumer team."

Ninety-six persons were recruited and assigned to one of two case management teams - either consumer or non-consumer. At baseline, demographic and clinical data were taken from the information system of the agency. Clients were interviewed about a month after they were assigned to a case management team and again one year later. A 16-item scale was constructed to measure satisfaction with mental health treatment throughout the service year. Clients were also asked to assess whether their case managers were helpful in a variety of case management functions.

Ninety-one of the original 94 participants in the project were interviewed one year later. Forty-six of the consumer case management clients and 45 of the non-consumer case management clients were interviewed. The average satisfaction score for clients served by the consumer team was 2.78 and the average satisfaction score for clients served by the non-consumer team was 3.10. Clients who perceived their case managers as understanding, caring, able to comfort, etc., were more satisfied with mental health services. It appeared that the characteristics of individual case managers and the more general elements of the working alliance were more important in explaining the differences in overall satisfaction with mental health treatment than whether the clients were served by a team of consumers or non-consumers.

Solomon, P. and Draine, J. (1996). Perspectives concerning consumers as case managers. Community Mental Health Journal, 32, 41-46.

Solomon and Draine state "consumer and non-consumer case managers participating in a randomized trial of consumer case management were interviewed regarding their perceptions of consumer and non-consumer case managers, their work and their clients. Consumer case managers were concerned about how they were accepted by other mental health professionals. The consumer team maintained less collateral contact with other professionals and more interpersonal contact with clients than the non-consumer team did. Consumer case managers did not show any greater signs of stress, diminished self esteem, or burnout than non-consumer case managers."

Ninety-six clients were randomly assigned to a team of consumer case managers operating in a consumer self-help organization or to a team of case managers operating as a service of a community mental health agency. In addition to usual employment requirements, the consumer case managers also had to meet criteria related to their mental illness. Case managers were interviewed at the beginning of the study, at six months, and at one year, individually and as teams, on several occasions. Both teams were approximately 50% male and 50% female. The consumer team tended to have more representation of minority groups, to be older, and to have a wider range of educational backgrounds. The majority in both teams had previously worked with persons with severe mental disabilities.

Consumer case managers did not have the usual clinical supports available to non-consumer case managers. The authors suggest mental health centers hire consumers as case managers and offer clinical support. Both case management teams were only somewhat likely to seek alternatives to mental health system service resources, and the consumer team did not show any more likelihood to do so than the non-consumer team. Case managers also had concerns about the acceptance of clients by non-mental health services. Case managers may need more training and direction in how to connect with community resources rather than depending on the mental health system for all client service needs. Functioning as a team proved difficult for both teams. Regardless of consumer or non-consumer status, case managers were more comfortable working individually with their clients than sharing responsibility with other team members. The characteristics and personalities of individual case managers appeared to be at least as important as their consumer/non-consumer status in influencing the case management relationship. Consumer case managers, however, tended to see their clients as somewhat less capable. This could be because of the youth and inexperience of the non-consumer team in the mental health system, or to an unusually high level of expectation from consumers who had achieved professional status while overcoming the stigma of mental illness. The main limitation of this study was its small sample size.

Stephens, C. L. and Belisle, K. C. (1993). The "consumer-as-provider" initiative. The Journal of Mental Health Administration, 20, 178-182.

According to the abstract, "The National Institute of Mental Health has provided funding in Region I (New England) to several technical assistance centers: the Center for Community Change through Housing and Supports (Vt.); the Human Resource Association of the Northeast (Mass.); and the recently funded National Empowerment Center (Mass.). These federally funded projects are focused on guiding the mental health field toward a more consumer-driven system. The authors have been involved with these organizations and also provide consultation along with Northern Rhode Island Community Mental Health Center (NRICMHC) staff and consumers to other counties and states on improving services for adults and children with longer-term psychiatric problems. The consulting team for NRICMHC has encountered some communities where the hiring of current or former consumers appeared to present a 'quick fix' for system problems rather than a reflection of more basic changes in attitudes and programs. Based on the authors' personal and family experiences, as well as their work experiences, they have re-examined some of the conventional wisdom in the rapidly evolving area of 'consumers as providers.'"

There is a risk that moving consumers toward being providers will support and continue myths, mistakes, and false distinctions that make the humanizing, normalizing, integrating, and reforming of community mental health services more difficult. The article reviews nine conventional wisdoms and provides alternatives to each. For example, a conventional wisdom is that agencies must hire "consumer providers" because it is commonly believed that administrators and providers of services have never been mental health consumers. The alternative belief is that agencies with a clear commitment to persons with severe or persistent mental illness will attract and keep a significant number of former and current consumers in their work force. Consumer services are strongest in agencies that evaluate applicants not only for their personal and professional experiences, but for their values, helping, advocacy skills, and openness to growth and learning. Mental health competencies are not automatically established by either an academic degree or a psychiatric hospitalization. The nine conventional wisdoms bring with them potentially damaging

policies. Rigidity in the definition of a consumer may promote further division and competition within the mental health system, among parties who already hold less power, status, and resources than are needed to maintain a community-based, rights-oriented system of care. There are six principles that the mental health force and systems should consider if they are to be inclusive and consumer-driven. One is that a broad-based affirmative-action plan can be of greater value to all consumers and providers than a focused consumer-as-provider initiative.

Surles, R. C. (1994). Can client outcomes be enhanced by integrating consumer peer specialists into intensive case management teams? <u>Evaluation Bulletin: New York State Office of Mental Health, 2,</u> No. 1.

> A growing number of mental health programs across the country are experimenting with employing mental health consumers as service providers. This research design allows for direct comparisons of outcomes for clients of the experimental consumer-professional model with outcomes for clients serviced by the pre-existing professional-only model. In addition, a third comparison group was included: professional case managers plus non-consumer paraprofessional workers, a group that allowed assessment of the effects of simply adding staff.

> Complete longitudinal data were collected for 104 clients, 61% of the 170 who agreed to participate in the research. A repeated measures analysis of variance model was used to compare outcomes among the three client groups. Overall, the results indicated a significant relationship between client outcomes and treatment condition for six measures. There was little evidence that the addition of non-consumer paraprofessionals resulted in improved client outcomes beyond those associated with regular ICM. There was strong evidence that integrating recovering consumers into ICM teams was associated with enhanced service effectiveness. Consumer-providers appear to bring unique characteristics and contributions to the mental health workplace.

Van Tosh, L and del Vecchio, P. (1998). <u>Consumer/Survivor-Operated Self-Help Programs: A Technical Report.</u> Unpublished manuscript.

> In light of the possible contribution self-help can make to the recovery process, to cost-effectiveness, and to the success of related fields, such as substance abuse, the Community Support Program (CSP) began to support various technical assistance initiatives to promote self-help. Jacqueline Parrish, a CSP staff member, led this promotion, in which manuals were developed, newsletters published, and drop-in centers started. New grant announcements were issued in 1988. The professional community was beginning to realize that mental health consumers should take an active role in treatment and that client-operated services were able to reach those who declined help from the formal mental health system. There were other good reasons for starting consumer-operated projects. The 13 projects demonstrated a variety of services and supports, including peer supports, consumer-operated businesses, and community education. These demonstration projects have been among the most important and innovative supported by CSP.

> The technical report by Van Tosh and del Vecchio includes three chapters. Chapter One reviews the consumer/survivor self-help movement; Chapter Two discusses various consumer/survivor-operated self-help programs; and Chapter Three discusses cross-site findings and recommendations.

Chapter One introduces the National Institute of Mental Health's Community Support Program, discusses methodology, and offers a literature review. An examination of the findings of these innovative consumer-operated services demonstration projects was conducted. A cross-project analysis found similarities and differences, made observations, and recommended ways to set up, operate, and evaluate consumer/survivor-run programs. A literature review of self-help programs, including over 80 pieces of literature, gives a brief history of the self-help movement and some background information, along with a definition of self-help. The chapter describes Alcoholics Anonymous, and the benefits and characteristics of self-help. The chapter goes on to describe the mental health consumer movement. Outside support for and benefits of consumer/survivor self-help are discussed, along with valuable and unique features of consumer/survivor self-help. Consumer/survivor self-help classifications are given. Funding, impact of the consumer/survivor self-help movement, and consumers/survivors as colleagues are also addressed. Evolution of mental health consumer/survivor-operated self-help programs is reviewed at length. Subtopics are history of consumer/survivor-operated programs; types of services offered; structure and organization of consumer/survivor-operated self-help programs; funding; program administration and leadership; staffing; populations served; program governance; research and evaluation; and interaction with other agencies.

Chapter Two describes 13 demonstration projects. It includes sites from California, Colorado, Indiana, Maine, Missouri, New Hampshire, New York, Oregon, Tennessee, Vermont, Washington, West Virginia, and Wisconsin. Documents reviewed from each project include original applications, annual continuation applications, related correspondence , final project reports, and evaluation findings. The following parts of the program are discussed: project goals; services and supports provided; client population served; organization of staff and other people involved with the program; board development; staff size, characteristics and training provided; reasonable accommodation practices; program materials developed; implementation issues; inter-organizational coordination; existence of other self-help programs before and after the demonstration grant; project budget; evaluation strategies and findings; and program continuation plans. This information may be skewed because it comes from self-reports created by the projects. Other materials were prepared by the State mental health authority personnel, who are not familiar with the day-to-day operations of the centers, which also may compromise validity. However, the study of the projects is still valuable.

Chapter Three describes cross-site findings and recommendations. The authors point out some methodological weaknesses with this approach. For example, since different service models were developed in very different environments, there is the chance that many outside factors may have changed the site and cross-site findings. Data are limited in their comprehensiveness and validity. Significant similarities and differences are presented in the following domains:

    1) Project goals

    2) Services provided

    3) Individuals served

    4) Organization and administration

5) Implementation issues and barriers

6) Successes and evaluation findings

7) Recommendations

The recommendations call for increased technical assistance and training, better planning, adequate funding and continuation, enhanced cooperation, expanded people-of-color representation, more research, and direct funding of projects. The summary emphasizes the need for more research about cost/benefit analysis, independence, the impact of self-help on specific sub-populations, recipient satisfaction with services, empowerment, and examining whether these programs serve those whose needs would not otherwise be met. The report calls for consumer/survivor involvement in every stage of the research process.

Van Tosh, L. (with Finkle, M., Hartman, B., Lewis, C., Plumlee, L., and Susko, M. A.). (1993). Working for a change: Employment of consumers/survivors in the design and provision of services for persons who are homeless and mentally disabled. Center for Mental Health Services, 1-27.

This 27-page document contains an Introduction, followed by sections entitled People Helping People, The Evolution of Mental Health Consumer/Survivor Participation in Providing Services, Emerging Employment Trends, Qualities of Mental Health Consumers/Survivors Working in the Areas of Mental Health and Homelessness, Descriptions of Roles of Mental Health Consumers/Survivors in Providing Services, Unique Issues of Mental Health Consumer/Survivors in Participating in the Provision of Services, Recommendations, References, and an Appendix of Workgroup Participants' Biographies. According to the author, this report represents the efforts of a group of current and past consumers of mental health services who explain the importance of consumer involvement in the design and delivery of services to persons with mental illness and homelessness. The report arises from a research demonstration project funded by the Center for Mental Health Services to develop and evaluate innovative service programs for persons who are homeless and mentally disabled. This author identifies the qualities and unique issues of consumer/survivor participation in the planning, delivery, and evaluation of services for persons who are homeless and mentally disabled. Major employment trends that contribute to the increasing participation of consumers/survivors in these areas are discussed. Issues that may affect future programs and initiatives designed to employ consumers are also explored. Finally, recommendations are made about the mental health system and the consumer/survivor/mental health self-help movement's attempts to keep developing good ways to help persons who are homeless and mentally disabled. This paper was thought about, organized, and written by consumer/survivors.

The People Helping People section discusses the self-help, consumer/survivor movement and issues that are especially important to it. The Evolution of Mental Health Consumer/Survivor Participation in Providing Services discusses the history of the mental health self-help movement as well as consumer/survivor-operated programs and other services for persons who are homeless and mentally disabled. Emerging Employment Trends discusses a sampling of trends that are emerging in the areas of mental health and homelessness. For example, the major social problems of homelessness and the increasing lack of decent, affordable housing and employment opportunities for persons who are homeless and mentally disabled highlight the need for more workers who are creative and dedicated to ending homelessness and poverty. In the section Qualities of Mental Health

Consumer/Survivors Working in the Areas of Mental Health and Homelessness, unique characteristics, which make consumers/survivors' especially suited to serve individuals who are homeless and have a mental disability, are discussed. Some of the characteristics include "systems knowledge" (how to get around within the network of people and organizations offering service), street-smarts, flexibility, and patience. Descriptions of Roles of Consumers/Survivors in Providing Services lists numerous roles in several service areas. For example, in-program planning and design job developer, program coordinator/director, housing developer, fund raiser, planner, and researcher are listed. In the section Unique Issues of Mental Health Consumers/Survivors Participating in the Provision of Services, numerous issues, such as professionalism, federal Social Security Insurance, stigmatization, and ability to sympathize, are discussed. Recommendations are made in the areas of job supports, education and training, recruitment issues, policy issues, and research. The author recognizes that consumers'/survivors' talent, diversity of opinion, and creativity have propelled the mental health self-help movement into several national debates and forums. The doors to involvement, participation, and development have begun to open.

White, B. J. and Madara, E. J. (eds). (1998). The self-help sourcebook: Your guide to community and online support groups. (Sixth edition). Denville, NJ: American Self-Help Clearinghouse.

This sourcebook is published every two years and has been used by many people who have diverse interests and who are looking for a group to meet their special needs. Alfred H. Katz states in the forward that this book does more than merely provide accurate information. The book marks a growing acceptance of the social movement of self-help groups.

An introductory section discusses how to use the sourcebook, how to find a group, how to form a group, and things you should know when contacting any group by phone or mail. This section also discusses the American and New Jersey Clearinghouses.

Chapter One introduces self-help groups and defines the term "self-help group." A section follows on understanding what self-help groups do and how they do it. This chapter also lists ten good ways to interact with a self-help group and ends with a list of writings by professionals about self-help.

Chapter Two discusses starting a group and makes suggestions about how to do that. Then it gives a guide for the group contact person, and ends with ten steps and suggestions for professionals.

Chapter Three discusses the internet and how to find groups on it, the commercial computer systems, the value of online groups, and other ways the internet may be helpful.

Chapter Four recommends that before trying to start an online group you find out if an online resource on your topic is already available. This chapter discusses figuring out what you want to create on the internet and then creating it.

Chapter Five provides research reviews of mental health groups, weight-loss groups, addiction-related groups, bereavement groups, diabetes groups, caregivers groups, cancer groups, and chronic-illness groups.

Chapter Six lists clearinghouses in the United States and numerous other countries.

Chapter Seven lists self-help groups in different special need areas, such as abuse, addictions, bereavement, disabilities, family, health, and mental health.

Chapter Eight gives specialty toll-free phone numbers.

Zinman, S. (1987). Definition of self-help groups. In Budd, S., Harp, H. T., and Zinman, S. (eds), <u>Reaching across: Mental health clients helping each other,</u> Riverside, CA: California Network of Mental Health Clients.

Zinman defines self-help groups as having sprung from and as being important to the "mental patient" liberation movement. She writes about freeing "mental patients" from their/our externalized and internalized bonds, of freeing ourselves from the stigmatized images of culture, family, and the "mental health system."

The essential characteristics of self-help groups are to be self-defined and client-controlled; to be totally voluntary and based on self-determination; to share power, responsibility and skill; and finally to treat people as people and not as diagnoses or labels. Self-help groups are effective because they allow us to learn control over our lives; to restore power and hope to clients; to offer spiritual and physical support; and to provide us with the tools to help ourselves. Self-help groups can be very different from each other and include support groups, independent living programs, drop-in/advocacy/independent living services, political action groups, client-run housing, self-supporting businesses, and theater groups. Zinman also addresses the bond between political action and services/support groups, noting that political action groups are very goal-oriented and lack the mutual-help services that support groups usually offer.

APPENDIX C

Source: Center for Health Workforce Planning Bureau of Health Care Access, Iowa Department of Public Health, *A Report Prioritizing a Potential Shortage of Licensed Health Care Professionals in Iowa*, May 2005, available at:
http://www.idph.state.ia.us/hpcdp/health_care_access.asp

This appendix includes recommendations noted as a part of the larger report cited above. Based on the findings of this report, the following recommendations are set forth:

1. All licensing boards should collect a uniform minimum data set of employment information regarding their constituents.

If licensing boards collected a minimum data set of employment information, then valuable data about potential workforce shortages could be examined and inconsistencies regarding data would be minimized. Lack of pertinent information and disparate information makes it difficult to draw appropriate conclusions from data that already exists. An in-depth review of the physician data (Appendices K and Q) illustrates the point. The Board of Medical Examiners lists 9,833 total active licensees as of 12/31/04. Of that number, 5,990 reside in Iowa. According to data from OSCEP, only 2,609 are employed as primary care physicians and mental health physicians. The differences between these numbers are significant and, depending on the data used, would yield vastly different findings.[Note 2] The most meaningful number regarding workforce shortage issues is the employment figures provided by OSCEP. Having uniform information and having it available from a single source would help insure its accuracy.

2. The work of Iowa's Office of Statewide Clinical Education Program should be expanded to include all health professionals.

The report of the National Conference of State Legislatures [9] states that the OSCEP project "is perhaps the country's premiere state health workforce database" (p.4). The University of Iowa has developed a computer-based tracking model that provides meaningful data about selected workforce variables. This model has been in continuous operation since the early 1970s and has a good record of providing invaluable data for employers, educators, researchers and others interested in the state's health workforce. Currently, OSCEP tracks demographic, educational, and employment data of every active primary care physician, mental health physician, dentist, pharmacist, physician assistant, and nurse practitioner. They have recently begun tracking the same information about registered nurses in the state. Their work should be extended to include all licensed and unlicensed health professions because of the value of the data.

3. Each profession should develop its own working definition of workforce shortage.

Many variables impact a potential shortage and differ among the professions. A working definition would provide parameters for measuring workforce shortage. Development of such a definition should be a collaborative effort with agencies at the national level. Information akin to that gathered by the U.S. Dept. of Health and Human Service's Bureau of Health Professions' shortage area designations[10] is needed not just for primary care, dental and mental health physicians but for all professions. Prediction models need to be developed to assist in recruiting and developing a well-trained, geographically accessible, and diverse health workforce.

4. Professional associations should closely monitor issues within their profession.

Most professional associations are suffering from declining membership but it will be imperative that organizations maintain viability in order to influence the educational standards and policy decisions for their profession. They will also be prime movers in efforts to recruit new members for the profession. These activities are reaching critical stages for the various Iowa mental health professional associations in the near future.

5. Health occupational trend data should be used in planning formal and continuing education programs.

This trend data can be used by educators in planning new programs and in recruitment of students. Educators also need to be cognizant of how these expected trends might impact the availability of student preceptors as well as clinical experiences. Additionally, there are implications for succession planning to replace experienced faculty and for incorporating continuing education programs to train and retrain licensed and unlicensed health professionals. There are also implications for exploring newer teaching methods such as e-learning or telecommunications' technology.

6. This study should be replicated using data from non-licensed health professionals.

A review of the BLS workforce projections for 2002-2012 indicates that a large increase in non-licensed health care professionals is expected.[11,12] Many factors contribute to this prediction. If the number of licensed professionals continues to decline, as is likely the case in Iowa, then one strategy that employers can use to satisfy staffing needs is to hire more non-professionals. They can provide on-the-job training to perform selected functions now done by licensed employees. A review of the ages of Iowa's non-licensed health workforce would augment information provided by this report and help support policy decisions.

Note 1: Certified Health Service Providers are licensed psychologists who have additional clinical training.

Note 2: The following explanation is helpful in understanding one aspect of the disparity in physician data. "On a per capita basis, Iowa graduated more new physicians per 100,000 population (11.7) than did the entire United States (6.4) and ranked 4th among the 46 states with medical schools in medical school graduates per capita" [11]

APPENDIX D

Strengthening Iowa's Mental Health and Disability Services Workforce: Building and Sustaining Competencies

THE CHALLENGE. There is a crisis nationally and in Iowa regarding the workforce that delivers mental health and disability services. It is characterized by serious workforce shortages, difficulty recruiting employees into careers and into positions in these fields, high turnover rates, lack of access to relevant and effective training, and the slow pace with which the evidence on effective care informs the practice of the workforce.

Demand for healthcare that is both clinically–effective and cost-effective has led to the proliferation of practice guidelines (such as those promulgated by the American Psychiatric Association) and to increasing demand for evidence-based approaches to behavioral health care (such as the Substance Abuse and Mental Health Services "Toolkits"). However, the fact that there is still wide variation in clinical practice patterns and failure to deliver care in accordance with established guidelines has generated concerns about the competence of the workforce.

A SOLUTION FOR IOWA. Any effort to address concerns about the quality or quantity of workers in the mental health and disabilities service system must have as its goal *sustainable, practical* approaches. The answers are not to be found solely among existing service providers, in our institutions of higher education, or in state government. What will serve Iowa's citizens best is a structure that brings together the strengths of all of these communities with a heightened focus on real-world solutions to the on-going crisis of having a competent, committed workforce in place to support people with mental illnesses and intellectual and developmental disabilities.

THE NEW VISION. The vision of the proposed Mental Health and Disability Services Center for Clinical Competence and Training Institute is to build a skilled mental health and disability services workforce, including consumers and their families, that will work in local communities, community mental health centers, key state agencies, and service organizations to implement efficient, appropriately applied, and evidence-based services that significantly expand the role of individuals in recovery and their families when appropriate, to participate in, ultimately direct, or accept responsibility for their own care; provide care and supports to others; and educate the workforce.

THE BUILDING BLOCKS. The implementation of the new vision for Iowa will build upon simple, practical approaches:

- The creation of a **Workforce Collaborative** to bring together the many skills, voices and talents needed to implement sustainable change.

- A series of tangible work products that address immediate and urgent needs in Iowa's current service system.

- Strengthening the competences of line supervisors—the lynch pin in supporting change and improving quality is the quality of supervision.

- Strengthening the competencies of staff that work with children, adolescents and their families.

- Addressing the needs of our emergency mental health crisis services statewide.

- Building capacity to serve people with co-occurring conditions, such as mental illnesses and addictive disorders, or mental illnesses and developmental disorders.

- Improving the competencies of front line staff, which spend the most time with people receiving services, yet often receive the least training.

- Supporting consumers of services and their families to become more effective partners and care givers, and to engage them in training the rest of the workforce.

- Providing incentives to recruit and retain highly skilled professionals.

Iowa is in the process of transforming its publicly funded mental health system to a consumer and family-driven system that embraces prevention, resiliency, and recovery as guiding principles. Implementing that goal requires shedding old stereotypes of mental illness and replacing them with new attitudes and services that support people with mental illnesses. In the midst of this transition, the mental health system faces a crisis in providing appropriate mental health services to forensic clients. Without systematic and quality training as well as attention to effective strategies needed for implementation of new practices, the realization of Iowa's transformation goals could be compromised.

Center for Clinical Competence and Training Institute

1. Creating a Center of Clinical Competence

This initiative will require dedicated in-state staff and resources to ensure that all relevant partners are included, and that the efforts to develop Iowa's capacities are a constant focus of attention. For the initial year of this effort, we are proposing to hire a Project Director and an administrative assistant to manage all of the elements of the development process; the Project Director should be someone of demonstrated planning and organizing skills, with a good understanding of behavioral and other disabilities services, with additional expertise in the working with both academic and practice communities. In addition, funds are proposed for logistics support to convene meetings, publish reports, and to engage the services of needed consultants.

2. Creating a Workforce Collaborative

Essential to the success of a statewide effort of this type is an infrastructure to identify and prioritize workforce problems, coordinate or implement interventions, and monitor outcomes. Perhaps most important, an infrastructure is necessary to link and leverage *existing* resources that are available within the state to strengthen its workforce. The functions of such an infrastructure would include, but not be limited to the following:

Leveraging existing resources by:

- Identifying and disseminating information about existing workforce development resources (clearinghouse function).

- Coordinating workforce development efforts among various public and private agencies to achieve efficiencies and reduce duplication of effort.

Linking Iowa's mental health and higher education systems in a coordinated effort to develop a pipeline of culturally diverse and appropriately trained mental health providers. This includes:

- Educating educators about current trends in service delivery as a strategy for fostering relevant curricula in the educational system

- Working with the mental health, higher education, licensing systems, and payers to improve career ladders in mental health within Iowa.

Assessing routinely the mental health workforce development needs within Iowa, including:

- The magnitude, characteristics, and causes, of recruitment and retention problems, including the impact of compensation and benefits

- The accessibility, relevance, and effectiveness of training and education resources/program.

Planning in the form of a biannual strategic plan on mental health workforce development and report on the status of this workforce will be conducted by the Collaborative.

Implementing interventions to strengthen the workforce.

Promoting employment of consumers, youth, and family members in the mental health workforce.

Disseminating best practices in workforce development to employers of the mental health workforce.

Advising Iowa's executive, legislative, and judicial branches on workforce issues and policy.

Applying for other potential sources of funds to support workforce development.

The structure of the Collaborative would include a General Membership, Executive Committee, Standing Councils, and ad hoc workgroups.

Persons in recovery, youth, and the parents of children and youth with emotional and mental problems would play a major role in all structures.

Technology, in the form of web-enabled conference calls, will be used for selected meetings to maximize efficiency, minimize time and travel-related meeting costs, and foster access for consumers and family members.

The collaborative can serve as the Advisory Council to the Institute, ensuring that the voices of key stakeholders are heard, and that all elements of the system are engaged in the selection, design, delivery and evaluation of the work of the Institute. The Collaborative sets the policy direction for the work of the Institute in strengthening Iowa's workforce.

The activities of the Collaborative would be the responsibility of the Project Director identified above in the Basic Infrastructure section; the Institute would staff the work of the Collaborative and provide its administrative home. Resources dedicated to this effort would include logistic support for meetings, development and dissemination of reports, and the services of content and process consultants to advise the process.

Special Initiatives

The Center for Clinical Competence/Training Institute should sponsor a series of inter-related initiatives as soon as basic infrastructure is in place. Based on the assessment of the MHDS, the following five initiatives should be funded during the first year of the Institute's development. The first initiative (focusing on supervision) is cross cutting and provides the foundation on which the successful dissemination of evidence-based practices can be built and sustained. The remaining five areas focus on areas of urgent need in Iowa's system of care, and addressing them in a manner consistent with the vision of the Institute (using evidence-based methods, incorporating the best science available, etc.) will provide credibility for further elaboration of the work of the Center/Institute.

3. Supervision

A critical element in successful system transformation is intervention at the level of service supervisors. Training clinicians and other direct-care workers in evidence-based practices requires an informed support system; the lynchpin in such a support system is the front-line supervisor. In its national work, The Annapolis Coalition has determined that there has been significant erosion in the role of supervision in service delivery; this has been the case in Iowa as well. The pressure for billable hours has shifted the role of clinical supervision away from the content of service delivery and toward more administrative and financial duties. A concentrated effort to provide training in effective supervision is a necessary core step in changing practice. Existing resources are inadequate to address the content of such training, much less to attend to the necessary policy and reimbursement strategies that will need to be developed to shift the system in the direction of evidence-based models.

The resources allocated here would provide for curriculum development and pilot implementation of supervisory training in the MHDS system of providers, as well as the development of relevant policy and protocol changes needed to ensure continuity in the dissemination of new models.

4. Improved Services for Children, Adolescents and Their Families

This is already an identified high priority for Iowa MHDS, and this funding would ensure that there are resources available to the system to support dissemination of evidence-based strategies. Funds would provide for the engagement of experts in identified best practices and for implementation of training sessions and development of fidelity monitoring technologies to ensure that practices are implemented in a way that is consistent with the scientific findings that drive the practice.

5. Improved Emergency Mental Health Crisis Services

Iowa's hospitals are struggling to meet the demands of persons with mental and developmental disorders in crisis, many of whom could be served both more effectively and in a more cost-effective manner by robust crisis and emergency mental health services, including such strategies as "Mental Health First Aid", peer supports, crisis prevention intervention, use of telephone "hotlines", and the like. Funding would provide for the engagement of key Iowa stakeholders, content experts in model design, and provision of basic training in new approaches to emergency mental health crisis services.

6. Co-occurring Disorders

Iowa MHDS has identified co-occurring disorders (especially mental and substance-use disorders) as a high priority population that is currently un-served or under-served. In addition, there are many individuals with co-occurring intellectual/development disorders and mental health/substance use disorders who are not receiving state of the art care. Funding would provide for statewide training on science-based interventions and for the engagement of content experts for curriculum design and training delivery.

7. Direct Care Workforce

Although there are efforts underway in Iowa to address the needs of the direct care workforce in the development disabilities area, more effort is needed there. According to the University of Iowa Center for Disabilities and Development, there is no centralized resource for specialized disability trainings in Iowa or funding assistance to assure trainings are accessible to all direct care workers. These efforts need to be expanded to begin to reach the direct care workforce in other areas of the MHDS service system, as well. Funding would provide for development of cross-disciplinary competencies, curriculum development, and training implementation for direct care workers in all MHDS service agencies.

8. Consumer and Family Training

Self-directed care is a cornerstone of contemporary practice, which has been recognized in the development disabilities field for some time, and is a hallmark of recovery- and resilience-oriented systems of care for people with mental and substance use conditions.

While often given lip service, consumers and families will not be able to engage in effective management and leadership of their recovery plans without training, education and supports. Funding will provide for the use of existing training models (e.g., NAMI's "Family-to-Family" and "Provider Education" tools, the Certified Peer Specialist training models, etc.) or the development of curricula specific to the needs and desires of Iowa's consumer communities.

9. Professional recruitment strategies

Iowa has experienced chronic shortages at the highest end of the workforce: psychiatrists, psychologists, master's level licensed social workers and advanced practice nurses. Under this special initiative, Iowa will establish s pool of dollars to offer financial incentives (stipends, loan forgiveness, and supplements) to individuals in the high-need categories who are willing to help meet the skills deficits, especially in our rural and frontier communities. We will select those strategies that have been demonstrated to provide results, and match them to candidates who seem most likely to contribute to our system over time. Consumers seeking services in programs for those with chronic and persistent mental illness will benefit from the recruitment, placement and retention of up to eight psychiatrists, doctoral level psychologists or nurse practitioners with mental health specialization. Once placed in programs service the chronically and persistently mentally ill, these practitioners will provide professional mental health services to Iowans that do not receive the services now.